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ABSTRACT

Progress in implementing the Individuals with Disabilities Education Act (IDEA) and recommendations to further promote its implementation via the 1995 legislative reauthorization process are examined. The purpose of the legislation and major court findings regarding its interpretation are discussed. Ten hearings conducted by the National Council on Disabilities, to elicit views of parents and students on the law's effectiveness and to gather recommendations for better implementation, are summarized, with testimony from witnesses in the following 10 theme areas: the "zero reject" provision of the law, assessment for eligibility and nondiscriminatory evaluation of students, providing for appropriate education, providing the least restrictive environment, parent participation in decision-making, procedural due process for students, services to transition students from school to activities after school, discretionary programs to help implement the law, provisions that determine the federal share of costs and how federal funds are allocated, and the 1994 federal educational reform law entitled the Educate America Act. Appendices include hearing dates, locations, participants and witnesses, and a synthesis regarding IDEA implementation based on 27 research papers. (SW)

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Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children

National Council on Disability

May 9, 1995

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National Council on Disability

**Improving the Implementation of the Individuals with Disabilities Education Act:
Making Schools Work for All of America's Children**

Publication date: May 9, 1995

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and the Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

LETTER OF TRANSMITTAL

May 9, 1995

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

The National Council on Disability is pleased to submit to you this report entitled, *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children*. This report presents the results of an extensive research process regarding progress in the implementation of the Individuals with Disabilities Education Act (IDEA) over the past 20 years and recommendations for improving the implementation of IDEA as Congress begins to consider its reauthorization. Nearly 400 witnesses (the vast majority of whom were parents of children with disabilities, students with disabilities themselves, and adults with disabilities) contributed their views regarding the reauthorization of IDEA at 10 regional hearings, sharing their experiences with IDEA to date and their hopes for its future. We believe that their voices should be central to any discussion of special education policy and that the adoption of the recommendations detailed in this report would result in a markedly improved special education service delivery system.

As you know, the right of students with disabilities to receive a free and appropriate education in the least restrictive environment is solidly rooted in the guarantee of equal protection under the law granted to all citizens under the Constitution. Over the past 20 years, the Federal government has recognized and supported this right through providing billions of dollars in special education funding in order to assist the States in meeting their responsibilities in this area. Our main finding is that this investment has had a positive impact on the quality of life experienced by students with disabilities and their families, and that the majority of problems which have occurred in special education have not been the result of problems with the law itself, but with its implementation.

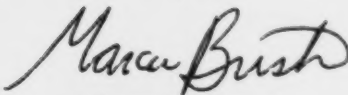
Therefore, the National Council on Disability recommends that the Federal government develop a more efficient and effective approach to monitoring the implementation of IDEA, identifying exemplary practices where they exist, citing non-compliance where it exists, delivering technical assistance aimed at improving compliance, and providing effective sanctions for non-compliance. Through improved implementation of IDEA,

**The President
May 9, 1995
Page Two**

education for all students can become "special," and all students will be supported in attaining their maximum potential in order to create a future for America that is characterized by acceptance of diversity, global competitiveness, and the full exercise of citizenship.

It remains an honor to serve you and America in this vital work.

Sincerely,

A handwritten signature in cursive script, reading "Marca Bristo".

**Marca Bristo
Chairperson**

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Most of all, the National Council wishes to thank the hundreds of parents, students with disabilities, adults with disabilities, and interested professionals who took time from their busy lives to attend the hearings and to present testimony on their experiences and their recommendations for the improvement of the Individuals with Disabilities Education Act.

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INTRODUCTION

With the passage of the Education for All Handicapped Children Act in 1975, the nation took a giant step forward in ensuring that students with disabilities and their families would be afforded equal protection under the law. As a result of numerous exposés, court cases, and the advocacy of parent groups, the Congress responded to the historic exclusion of children with disabilities with a guarantee that children with disabilities would be afforded equal educational opportunities and the supports and services necessary to access such opportunities. Congress not only granted a right to education for all students with disabilities, it also established the mechanisms through which students and families could exercise that right. Among its many provisions, the Education for All Handicapped Children Act required parent participation at virtually all levels, fair assessment practices, the development of an individualized education program for every eligible student, the provision of related services, placement of students in the least restrictive environment, and the establishment of due process procedures through which parents and students could appeal the decisions of professionals.

A summary of the provisions of the Act and major court findings regarding its interpretation follows.

Reviewing IDEA's Purposes

Congressional Purposes

In 1975, when Congress enacted the Education for All Handicapped Children Act, P.L. 94-142 —now titled Part B of Individuals with Disabilities Education Act (IDEA)— it found that the special education needs of more than eight million students with disabilities were not being met. Some students were entirely excluded from school; others were not receiving an appropriate education; still others had unidentified disabilities or were misclassified. Of those who did receive educational services, many were educated far away from their local schools (20 U.S.C. Sec. 1400(b)(1)-(6)). Still, Congress recognized that educators had the ability to instruct these students (20 U.S.C. Sec. 1400(b)(7)).

Congress then found that State and local educational agencies had a duty to educate all students with disabilities, that they lacked the financial resources to do so, and that it was in the national interest for the Federal government to assist in meeting the educational needs of students with disabilities in order to assure equal protection under the law (20 U.S.C. Sec. 1400(b)(8) and (9)). Accordingly, Congress declared that the Act's purpose was to assure that all children with disabilities receive a free appropriate public education; to ensure that their rights and those of their parents and guardians were protected; to assist State and local agencies in providing for their

education; and to assess and assure the effectiveness of those agencies' efforts to educate students with disabilities (20 U.S.C. Sec. 1400(c)).

The 1995 Reauthorization

Every time that Congress has reauthorized or amended IDEA during the last 20 years, it has strengthened and extended IDEA's substantive and procedural provisions. In doing so, it has reaffirmed the original statement of purpose. In 1995, the 104th Congress has every reason to follow this unbroken precedent for the following reasons:

- ◆ There is more than a 20-year history of Federal presence in special education. P.L. 94-142 was not the first (although it was the most comprehensive) Federal special education law. Its predecessor was the Elementary and Secondary Education Act of 1965 (P.L. 89-750) as amended by the Education of the Handicapped Act (P.L. 91-230 and P.L. 93-380).
- ◆ Congress has long been committed to enabling people with disabilities to work and participate in economic benefits of our country. Through initial passage of and ongoing and strong support for legislation such as the Rehabilitation Act Amendments of 1973, IDEA itself, the Americans with Disabilities Act, and the Developmental Disabilities Assistance and Bill of Rights Act, Congress has expressed its strong and unwavering support for ensuring that people with disabilities are afforded equal protection rights granted under the Constitution (including equal educational opportunities), and are protected from discrimination, as well as for ensuring that State and local governments receive assistance in providing effective services to people with disabilities.
- ◆ Finally, every branch of the Federal government has acknowledged that IDEA is fully justified. This is true of the Legislative Branch and the Executive Branch, and especially true of the Federal courts, the Judicial Branch. Indeed, the United States Supreme Court itself has uniformly and often unanimously upheld IDEA's basic principles:

- ◆ *By passing (IDEA), Congress sought primarily to make public education available to handicapped children...to open the door of public education to handicapped children...to incorporate and build on the principles established in two 1972 decisions, PARC v. Commonwealth and Mills v. D. C. Board of Education (the principles which they established are the principles which, to a significant extent, guided the drafters of the Act)...to provide federal assistance to enable the states to meet the needs of the children (citing H.Rep. No. 94-332), and thereby to create...access to specialized instruction and related services which are individually designed to provide educational benefit to the handicapped child. Board of Education v. Rowley, 458 U.S. 176 (1982).*
- ◆ *A service [such as clean intermittent catheterization (CIC)] that enables a handicapped child to remain at school during the day is an important means of providing the child with the meaningful access to education that Congress envisioned....Services like CIC that permit a child to remain at school during the day are no less related to the effort to educate than are services that enable the child to reach, enter, or exit the school. Irving Independent School District v. Tatro, 468 U.S. 883 (1984).*

The Court has made it clear that IDEA is not one of the so-called "unfunded Federal mandates," but is a Federal grant program that is entirely justified under Congress' power and duty to implement the equal protection guarantees of the U.S. Constitution. More than that, the Court has acknowledged in the most unequivocal terms that IDEA provides Federal aid to the States to help them carry out their own legal obligations to educate all children, including those with disabilities.

The [IDEA] is a comprehensive scheme set up by Congress to aid the States in complying with their constitutional obligations to provide public education for handicapped children. Both the provisions of the statute and its legislative history indicate that Congress intended handicapped children with constitutional claims to a free appropriate public education to pursue those claims through the carefully tailored administrative and judicial mechanism set out in the statute....The [IDEA] was an attempt to relieve the fiscal burden placed on States and localities by their responsibility to provide education for all handicapped children [citations omitted] At the same time, however, Congress made clear that the [IDEA] is not simply a funding

statute. The responsibility for providing the required education remains on the States [citations omitted] And the Act establishes an enforceable substantive right to a free appropriate public education. Smith v. Robinson, 468 U.S. 992, 1009, 1010 (1984).

These cases build, as does IDEA, on the cutting edge honed by two 1972 decisions.

- ◆ By a consent decree, PARC v. Commonwealth, 334 F. Supp. 1257, 343 F. Supp. 279 (E.D.Pa. 1971, 1972), which ordered the State to provide all school-aged children with mental retardation in Pennsylvania a free appropriate public education in the least restrictive placement. The court found that the denial of that right constitutes a denial of their equal protection guarantees: *Having undertaken to provide a free public education to all of its children, including its mentally retarded children, the Commonwealth of Pennsylvania may not deny any mentally retarded child access to a free program of education and training.*
- ◆ By a decision and judgment, Mills v. D. C. Board of Education, 348 F. Supp. 866 (D.D.C. 1972), which held that the District of Columbia Board of Education has an obligation under the due process clause of the Fifth Amendment to provide a free and suitable publicly supported education to every school-aged child, regardless of the student's degree of mental, physical, or emotional disability.

Twenty Years Later: Has IDEA Met the Test of Time?

In the 20 years that have passed since the enactment of the Education for All Handicapped Children Act, significant changes have occurred in our society and in our schools. Numerous calls for educational reform have been made and ambitious plans for improving the performance of the nation's schools have been launched, most notably the Goals 2000: Educate America Act. Within this climate of educational change, it is imperative that special education become more closely aligned with regular education.

Indeed, it is of the utmost importance that special education not exist as a separate entity, but that it assume the role of a supportive service within the context of regular education. Both systems have a lot to learn from each other, and if special education is to prosper under efforts at educational reform, it must be better woven into the fabric of modern education.

In addition to changes in the field of education, many changes have occurred during the last 20 years in our nation's policies regarding people with disabilities. In this relatively short period, the foundation of disability policy has shifted from a base largely built on paternalism to one built on civil rights. Today, the stated goals of the nation's disability policy—as defined in the landmark Americans with Disabilities Act of 1990—are *to assure equality of opportunity, full participation, independent living, and economic self-sufficiency.*

Given these changes in society, in schools, and in disability policy, it is important to understand whether legislation developed during the 1970s is meeting the needs of students, families, and professionals who are living in the 1990s. While the original Education for All Handicapped Children Act has been changed through various reauthorizations, its fundamental goals and features have remained intact. Today, the Act's successor, the Individuals with Disabilities Education Act (IDEA), contains important *additions* that have been made over the years in areas such as research on promising practices, extension of coverage to infants and toddlers, provisions for better

transition to adult life, etc. However, IDEA largely retains the original goals and features of the Education for All Handicapped Children Act. As IDEA is currently scheduled for reauthorization, the National Council on Disability (NCD) determined that it should conduct a field-based study of the status of IDEA and develop recommendations regarding its reauthorization.

The National Council on Disability has a special interest and responsibility in ensuring that the Individuals with Disabilities Education Act responds as fully as possible to the needs of children and youth with disabilities. This interest and responsibility are based on its historical affiliation with the Department of Education, our continuing statutory responsibilities involving the Department, and its statutory mandate to provide Congress and the Administration with advice and recommendations on all aspects of disability policy.¹

Accordingly, the National Council on Disability determined that the best method for gathering information on the status and impact of IDEA would be to conduct of field hearings across the country, hearings designed to gather information from those who were in the best position to comment on the law's effectiveness: parents and students. Through 10 field hearings held during October and November 1994 in Alaska, New

¹ See, for example, National Council on Disability (1994). *Inclusionary education for students with disabilities: Keeping the promise*. Washington, DC: Author; and National Council on Disability (1993). *Serving the nation's students with disabilities: Progress and prospects*. Washington, DC: Author.

Mexico, Iowa, New York, Pennsylvania, North Carolina, Wisconsin, Colorado, Massachusetts, and California, the NCD was able to develop a rich data base from which to determine the current level of the law's effectiveness and to make recommendations for its improvement. These hearings were held in each region of the U.S. Department of Education in order to develop a profile of special education practices by focusing on the experiences of parents, family members, students, adults with disabilities, and other interested people with a family-based perspective. (Please refer to Appendix A for a list of hearing dates and locations). The hearings were designed to encourage cross-disability participation and testimony from minority citizens. In recognition of the evolving role of government in the lives of citizens across the United States², NCD's focus was primarily on the "customers" of special education: parents, family members, and students themselves. This focus on the views of parents and students is based on the belief that the ultimate test of the effectiveness of government programs is whether those programs have a positive, real, and lasting influence on the lives of those they are designed to help. The goals for the hearings were to identify areas of strength in the current implementation of IDEA and to gather recommendations for better implementation from the viewpoint of customers.

At these hearings the NCD heard from nearly 400 witnesses, most of whom were parents or other family members of students with disabilities. Past and present students

² See Gore, A. (1993). *From red tape to results: Creating a government that works better and costs less*. Washington, DC: U.S. Government Printing Office.

and a relatively small number of professionals also testified³. In all, the hearings produced over 3,000 pages of transcripts, written testimony, and letters regarding the substance of the hearings. Consistent with its goal of presenting the views of the customers of special education, NCD has included direct quotes from approximately half of the witnesses who testified at the hearings in the present report.

The NCD was assisted in conducting these hearings by Centers for Independent Living (responsible for organizing hearings in Alaska, Pennsylvania, and Wisconsin), State chapters of The Arc (responsible for organizing hearings in New Mexico, Iowa, and North Carolina), and Technical Assistance to Parent Programs (responsible for organizing hearings in New York, Colorado, Massachusetts, and California). The Beach Center on Families and Disability (University of Kansas) also assisted the NCD with logistics concerning the hearings. In addition, Beach Center staff read and indexed (by witness and topic) all of the testimony and prepared a summary and analysis for the NCD that form the basis for this report.

The overall finding associated with this research process is that the basic principles and features associated with the Individuals with Disabilities Education Act

³ As stated earlier, the goal of the hearings was to gather information from parents, family members, and students. The NCD relied on local groups to organize the hearings, groups which employed varying levels of publicity regarding this goal. As a result, approximately 15% of the witnesses were professionals. However, the majority of these professionals were employed by parent training and disability advocacy organizations. Therefore, the vast bulk of testimony was from a customer perspective.

are as valid today as they were 20 years ago. Thus, very little language in the Act needs amendment. However, given extensive and at times very serious and negative reports from parents and students regarding the impact of IDEA on their lives, vast improvement in the implementation of the Act is needed. Dramatic improvements are needed in implementing policies and programs across all major parts of IDEA.

Common themes heard throughout the hearings included the following:

- ◆ Far too many school buildings remain physically inaccessible to students with disabilities, thereby denying these students placement in regular educational settings. In addition, contrary to the provisions of the Act, some students continue to be excluded/ removed from school based on behaviors associated with their disabilities.

- ◆ The current system of identifying students as eligible for special education encourages the harmful labeling of children, fails to identify some needy students as eligible, overidentifies children from minority backgrounds as disabled, and often employs assessment criteria that are inappropriate for students or insensitive to their cultural and communication backgrounds.

- ◆ There is great variability in the quality of individualized education programs (IEPs) required under the Act. The overall purposes of IEPs must be clarified. IEPs need to be supported by better parent training, more parental flexibility regarding the contents of IEPs, and monitoring for improvements in the level of parental satisfaction with the process and its results.

- ◆ In spite of provisions requiring placement in the least restrictive environment, many parents reported that placement in a regular school building was simply not an option offered in many school districts. In fact, there are financial incentives to place students in separate facilities. Virtually all of the parents who had gained inclusive placements for their children reported that they had to fight for these placements, sometimes via legal proceedings. Nevertheless, these parents universally stated that these inclusive placements were far superior to segregated placements.

- ◆ The field of special education needs to undergo a paradigm shift, from its current status as a system apart from regular education to one which is an integral part of regular education, providing a wide array of supports and services within the context of regular education programs and facilities. Services and supports should come to students, not the other way around.

◆ In spite of provisions mandating parent participation in decision making, parents in many parts of the country still feel largely left out of the process. Many parents reported that they arrived at IEP planning meetings only to be presented with a completed plan.

◆ The Federal government should play a key role in monitoring the quality of special education and enforcing the provisions of the Act. However, there are serious problems with the type and frequency of current Federal monitoring activities. These problems essentially condone non-compliance with the Act and increase parental use of the due process provisions of the Act, placing serious financial hardships on families and creating adversarial relationships between school districts and families.

◆ Parents should have a voluntary option to use mediation and other forms of informal dispute resolution when disagreements with school districts occur.

◆ The mandatory age for transition planning should be lowered to 14 and students should be better prepared for their transition from school to adult life through more flexibility in secondary school programming.

◆ The family-centered focus of Part H of the Act relating to infant and toddler services has been both well received and beneficial. Consideration needs to be given to having this family-centered focus throughout the Act.

◆ Personnel preparation programs need to produce graduates who have the skills and experience to provide intensive developmental and remedial instruction to students with disabilities in regular education settings.

◆ Funding for parent training programs needs to be increased if parents are to become well-informed and effective partners in the educational process.

◆ Based on the implementation of the recommendations in this report for the restructuring of special education, overall Federal funding for special education should be increased.

◆ Special education should be an integral part of the implementation of Goals 2000. Its role should change from a *place* where a limited number of labeled students are sent to a *support service for all learners* in schools all across America.

In the chapters that follow, the text describes the testimony of witnesses regarding these themes and their recommendations for improving special education. It

is necessary to emphasize, however, that in spite of the many problems reported by witnesses, strong support was present at every hearing for the continuation and improvement of IDEA. Even within the context of flawed implementation and limited funding, IDEA has made a remarkable difference in the lives of many it has served. What is needed now is significantly improved implementation, leading to a better education for all children. It is our belief that the customer-driven recommendations contained in this report will lead to this end.

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT: TWENTY YEARS OF PROGRESS IN EDUCATING THE NATION'S STUDENTS WITH DISABILITIES

IDEA has made a difference for Maddie, a difference that translates into her attendance at our public elementary school a half a block from our home with other first and second graders in her neighborhood. Her regular presence in school means that kids of all ages greet her on the playground, acknowledge her in stores, and expect that she is a part of the community. As a result of these expectations, I'm proud to say that Maddie could not be here today -because she is in school! (Joe Wild Crea, Denver, CO)⁴

Before IDEA the vast majority of children with disabilities had no future. IDEA has created a future with real opportunities. It must be reauthorized. As we've heard, it's a great success in human terms, but it's also a great success in cold, hard economic terms because educated children with disabilities are growing up and becoming productive adult taxpayers. (Stanley Klein, Boston, MA)

I love IDEA. It's a wonderful law. Keep it...Strengthen the ability to monitor and enforce the laws, take out of the way barriers that don't allow for the integration imperative to be realized, provide incentives to help teachers keep abreast of the state-of-the-art technologies (instructional, as well as assistive), that are allowing our young people to achieve so much. (Janet Vohs, Boston, MA)

Across the nation, parents, family members, and students with disabilities, as well as advocates and friends enthusiastically reported on the positive impact the Individuals with Disabilities Education Act (IDEA) had in their lives and encouraged

⁴ We have endeavored to spell witnesses' names correctly. Some were difficult to read on sign-in sheets. The court reporters at the hearings worked hard to ensure correct spelling. Still, we apologize for any errors. All quotes are verbatim, with the exception that punctuation has been added for clarity, pauses have been omitted, verb tenses have been aligned, and obvious repetitions within quotes have been condensed. Also, the location listed is the hearing location, not necessarily the actual address of the witness.

Congress to "fine-tune" the statute in order to ensure more effective implementation by Federal, State, and local educational agencies. In all of the 10 regional hearings sponsored by the National Council on Disability there were ringing affirmations in support of IDEA and the positive difference it has had in the lives of children and youth with disabilities and their families.

I think there's a whole generation of parents out there who could give you story after story of what it was like before and after enactment of the IDEA. And the difference is dramatic in what we could expect for our children....The benefits of IDEA have been enormous, and throughout the country there are exemplary programs and dedicated professionals working hard every day to make the law work. (Diane Lipton, Berkeley, CA)

I try to appreciate all the opportunities that I have had to achieve, but when I leave school, I want a real job with a company that is willing to pay my salary and be patient with me...I would become a total product of what you all decided I am going to be, as you all have a say in all my dreams and goals. What gives you the right to place limits on me? Remember, that in this life, we all have had dreams. All of you, you need to give people like me an opportunity to fulfill our dreams, to be accepted by everyone in this community, and most important, to attend schools and live and work in a normal environment. (Nannie Marie Sanchez, Albuquerque, NM)

This is a critical law that has a powerful impact on our children, our family and our community. Don't change it. Fund it and enforce it. (Linda Breuer, Milwaukee, WI)

In hearings all across the country, witnesses told of the tremendous power of IDEA to help children fulfill their dreams to learn, to grow, and to mature. For many, the opportunity to be included in regular education classrooms with special education supports in place meant meaningful education that prepared them to enter the adult world as active contributors, rather than dependent (and largely unknown) "outsiders." Witnesses told of school districts where children with disabilities were made welcome,

were accommodated, and were viewed as participating members of the school community. As one witness put it, the education system, and society at large, must

Recognize that disabled children are a part of the American Family. Without the law, without each and every protection, equal educational opportunity for disabled children will again be an empty dream. (Diane Lipton, Berkeley, CA)

These people had seen IDEA working as it should, with both the education community and families accepting responsibility for children with disabilities, providing them access and opportunities for growth and learning and helping them to enjoy the free and appropriate public education which the IDEA promises.

Many witnesses testified to the positive difference that IDEA has made.

However, many others pointed out that IDEA has not achieved all that it might, even as the nation reaches IDEA's 20th anniversary:

The principal told me... my child was a miserable failure because he could not perform math without assistance. (Jan Miller, Berkeley, CA)

Sitting on top of their disabilities, like oil on water, is this large layer of, "I can't. Why even try?" (Judi Hirsch, Berkeley, CA)

The witnesses were overwhelmingly clear that there is a great deal more that Congress, the U.S. Department of Education, and State and local agencies can do to assure the equal protection of the law and to improve IDEA's implementation. There are still far too many shortcomings in special education practice, yet not a single one of the almost 400 witnesses advocated for anything but the fine tuning of IDEA itself. What

they wanted, almost unanimously, was improvement in practices, not in the Act itself. One witness, summing up the sentiment of all who testified, made the following statement:

If IDEA should not be reauthorized, it would make our plight, as well as thousands of others, a catastrophe. (Carolyn Lavadie, Albuquerque, NM)

Another witness also expressed the sentiment of others, firmly stating her belief that the implementation of IDEA can be greatly improved:

I think we need leadership on all levels: nationally, the state level, and certainly within the school districts in the school system. That leadership, once in place, will move mountains. (Rafaelita Bachicha, Albuquerque, NM)

Throughout the hearings, witnesses provided testimony regarding virtually every aspect of the law. Their testimony was organized around 10 basic themes which encompass both the historic and the current implementation of IDEA:

- ◆ *Zero Reject*, the provision that requires that all students, regardless of the nature or severity of their disabilities, shall receive a free and appropriate public education;
- ◆ *Assessment for Eligibility and Nondiscriminatory Evaluation*, the provisions that requires State and local education agencies to assess students fairly for strengths and needs and then determine whether a student has a disability, the nature and extent of the disability, and the student's need for special education;
- ◆ *Appropriate Education*, the provision that requires education agencies to follow certain processes in educating students in special education (including the development of an individualized education program) and to assure that they benefit from their education;
- ◆ *Least Restrictive Environment*, the provision that requires education agencies to educate all students with disabilities with students who do not have disabilities to the maximum extent appropriate;

- ◆ *Parent Participation*, the provisions that enable education agencies, parents, and students to share decision-making responsibilities and to collaborate in special education;
- ◆ *Procedural Due Process*, the provisions that require education agencies to be accountable to parents and students;
- ◆ *Transition*, the provisions that require education agencies to follow certain procedures to ensure that students will have the skills and opportunities to achieve certain goals as a result of their experience in special education;
- ◆ *Discretionary Programs*, the provisions for those training, demonstration, research, and technical assistance programs that Congress has authorized to help Federal, State, and local agencies carry out their duties and to help parents and families be effective partners;
- ◆ *Funding*, the provisions that determine the Federal share of special education costs and how Federal funds are being allocated; and
- ◆ *The Goals 2000: Educate America Act*, the nation's education reform law (P.L. 103-227), with provisions that give particular attention to how families, students, and professionals in special education are involved in its implementation.

The witnesses' concerns paralleled those that NCD discovered as it analyzed the research literature on IDEA's effectiveness and how it might be improved at the Federal, State, and local levels. In fact, NCD, in collaboration with the Beach Center on Families and Disability, commissioned 27 research papers by preeminent scholars in special education research and personnel preparation: these papers were written concurrently with the hearings. The degree of similarity between what witnesses told NCD at the hearings and what these scholars cited as the most important areas for attention during the reauthorization process was remarkable. Appendix B contains a brief synthesis of these papers. Thus, there emerge from two sources—from consumers as well as researchers and teacher trainers—generally consistent and always powerful

messages: *IDEA has had a powerful positive impact. It redresses the denial of equal educational opportunity. It needs fine-tuning. Most of all, it needs effective implementation and reauthorization.*

A great leader once said, "A single spark starts an enormous fire." Ladies and gentlemen, IDEA is the spark that started a fire within the souls of many who experience mental retardation and other disabilities and their families. We must allow the fire to fully ignite opportunity for all children with disabilities. It is imperative that IDEA be properly reauthorized so that these children and their families can realize the same choices and opportunity as all Americans. (Mike Remus, Des Moines, IA)

The law may be named "the Individuals with Disabilities Education Act", but for children like my daughter and others, it really means ideas, dreams, expectations, and aspirations. Because...through IDEA, we will see our dreams come to life for our children. (Sue Endress, Milwaukee, WI)

I came from Minnesota today because in my work I often say I marvel at how well this law was written. I marvel at a law that was written in 1975 that did not anticipate many of the needs of the children who are in the system now. I marvel at how well that system does serve children if there is a spirit of a partnership between professionals and parents. (Virginia Richardson, Des Moines, IA)

A partially implemented IDEA has transformed thousands of lives and hundreds of communities. The Arc of Nebraska and this parent would like to see it taken to the next level. There are hundreds with dreams like John who are counting on you and me to get IDEA reauthorized. They need us, and we need them to experience full communities where everyone participates and contributes...We learn to see similarities rather than differences and to live in the real world with diversity. Many people will tell you that they have become more informed, more sensitive, more productive, and more loving in their relationships with persons with disabilities. In a world torn with greed, apathy, prejudice, and waste, the inclusion of persons with developmental disabilities offers communities a better way. They are here to participate and teach us as well as to learn with us. (Gwen McCollum, Des Moines, IA)

The chapters which follow provide a detailed summary, across the 10 thematic areas, of the varied experiences and recommendations of people testifying at the

hearings. However, it is important to remember that all agreed that IDEA should be reauthorized and that the most helpful and relevant Federal action at this point would be to strengthen its implementation and enforcement.

ZERO REJECT

Statement of Law

Congress demonstrated a low tolerance for the exclusion of students with disabilities from the education system when it enacted the IDEA. Through the development of a principle which has come to be known as "zero reject," Congress required education agencies to provide all students, regardless of the nature or severity of their disabilities, with a free and appropriate public education. While the term "zero reject" is not found in IDEA's language, the concept is firmly embedded in the statute. Congress unequivocally declared that the purpose of IDEA is to assure that *all* children with disabilities receive a free appropriate public education (20 U.S.C. 1400(c)).

Witnesses at the hearings discussed the principle of zero reject, often in conjunction with other areas of concern such as appropriate education or the principle of the least restrictive environment. However, witnesses also had specific stories to tell concerning access, schools' exploitation of parents' lack of knowledge, and the exclusion of difficult-to-serve students.

Access

Although the only thing I needed was an accessible bus to take me to school, I was denied admittance to Girl's High. (Suzanne Bacal, Philadelphia, PA)

Why should it be that when a child shows up with a visible disability, say in a wheelchair or something, why is that child still automatically stuck in the dark room in the back? Believe me, the dark rooms in the back still exist. (Barbara Anderson, Milwaukee, WI)

In city after city witnesses complained of physical barriers in schools. They testified that there are still architectural barriers in school buildings and elsewhere in the community that make access difficult for those individuals requiring accommodations. Of the greatest concern to hearing participants is the inaccessibility of many areas for wheelchairs and the dearth of elevators that are in working order.

I was expected to stay back and be part of the special 6th grade because that school had an elevator and the school I was going to had steps. I learned to climb steps that summer. (Bernadette Griffin, Philadelphia, PA)

The school does not have any facility for handicapped [students] in the restrooms, none whatsoever. (Michael Kidd, Charlotte, NC)

Another concern in the schools is the physical accessibility to the classrooms and also to the bathrooms. (Rebecca Campbell, Anchorage, AK)

Educators' lack of awareness regarding the specific nature of these barriers and how they effect students with disabilities was especially problematic:

Make it clear that all SEAs, IEAs, AEAs, and LEAs are bound by the provisions of Americans with Disabilities Act. Frequently today an SEA will ignore all allegations of discrimination on the remarkable theory that discrimination is a civil rights issue, not an education issue. The fact is that the two issues go hand in hand...By separating the two, the SEA, the AEAs and the LEAs are effectively perpetuating the patterns of discrimination. (Denita Swenson, Des Moines, IA)

Parents' Lack of Information

One reason exclusion exists is that some school districts effectively exploit parents' lack of knowledge regarding their children's rights under IDEA. Parents tend to view professionals as authority figures. With great frustration, they often accept

decisions of professionals not to provide their children with disabilities with special education and related services:

We had no idea what the law was...and even though we begged and begged for them to do something with him to help him learn, they wouldn't do anything. Every year he fell further and further behind. We were told when he was fourteen, by the principal, "I wouldn't worry. In a couple of years he'll be sixteen and he can quit." (Barbara Anderson, Milwaukee, WI)

Many witnesses also pointed out that exclusion sometimes exists because non-English speaking parents lack understanding of the special education system. Although their children must be evaluated in their own first language, these parents are not advised in any language other than English. This places them in a situation where they have no alternative other than to accept whatever decision is made by the schools, even if it is to exclude the child.

Difficult-To-Serve Students

Exclusion is also occurring because State or local education agencies lack the ability or willingness serve children with severe, complex or difficult-to-serve disabilities. Witnesses recounted tales of students being passed from teacher to teacher and school to school in an effort to push them out of the system as quickly as possible. In some extreme situations, schools simply advised parents that their children were not welcome within their classrooms and refused to admit them. In other situations, students were admitted, but schools then refused to educate them or provide necessary services to meet their needs.

I had a mom tell me that someone within the Mat-Su District told her, "Don't send your son to school. He's out of it anyhow. He's not going to get anything out of school." (Elaine Hurley, Anchorage, AK)

Many witnesses expressed concern regarding (1) the lack of available resources for children with behavior and emotional difficulties, (2) school districts that do not recognize behavioral difficulties (such as attention deficit disorder) as a disability, and (3) the lack of services for children with medical needs, including disputes regarding LEA obligations to provide related services to them. Too often, children with behavioral and emotional difficulties are shuffled throughout the local system until they are either "forced" to leave school or until they are incarcerated. In addition, local agencies refuse to recognize behavioral, emotional, or attention deficit disabilities, despite a medical diagnosis or the results of private evaluations. These agencies provide no interventions or services, or they expel students when their disabilities become too troublesome.

Discipline

In most cases...educational professionals use the following technique to deal with students who have emotional and behavioral problems: suspensions. This is not the answer to a child's disability. This action does not deter inappropriate behaviors. This action has not been shown to be effective in either changing behavior or improving the quality of education for students with behavioral disorders. (Pam Zacha, Charlotte, NC)

I do believe that children with disabilities right now are incurring a bad rap that they don't entirely deserve. I am here freely to admit that yes, some of those who are violent at school are children with disabilities, but some of the violence we see has nothing to do with disabilities as is defined in the law. (Virginia Richardson, Des Moines, IA)

Of the witnesses who spoke regarding discipline, there was little variance in the tone and tenor of their testimony. Three recurrent themes permeated their content in varying degrees, all recounting an unfortunately similar tale. These are stories of children who were suspended, expelled, or abused in direct violation of IDEA.

Witnesses routinely recounted incidents of children who had behavioral or emotional disorders or attention deficit disorders being suspended because a local agency would not provide appropriate modifications and interventions. Ironically, those children were being removed from schools because of the same behaviors that qualified them for special education in the first place.

What is happening right now is that a lot of students who have severe behavior problems are literally being kicked out of school... They are not allowed to have the services met in alternative settings and [as] the door is closed to providing services in various settings as the needs require, more and more students with severe emotional problems and severe behavior disorders will not have any educational opportunity. (Charlotte Des Jardins, Milwaukee, WI)

Keep [the] "stay-put" procedures. Suspension and expulsion procedures should protect children. Too many children I know have been excluded from appropriate schools because of inappropriate support and inadequate implementation of IEPs. (Jan Serak, Milwaukee, WI)

When we get into who is not being served in education, it is kids with behavior problems, and that's pretty much across the State, particularly in small districts. They are the ones who are suspended, and then you go through those nightmare processes trying to figure out specifically what the intent of the law is in dealing with these children. (Patty Jennings, Albuquerque, NM)

Many witnesses indicated that the apparent intent of various local education agencies was to remove their children from the schools permanently. Offered

unacceptable alternatives, parents have no choice but to keep their children at home, isolated from their peers, without the learning opportunities guaranteed under the law.

The school continued to call, and we continued to share the supports and services we knew needed to be in place, with the same results. "We can't. We won't. We tried. We don't have time. We have 49 other students. Emily is going to have to learn not to do that. She can't be with her peers because that's not where the special education teacher is." Emily communicated her frustrations with this very strongly, and the school listened to her by calling the police. So Emily is home again. (Jerri Miller, Denver, CO)

Witnesses also testified that abusive action toward children is an ongoing problem:

Repeatedly my son came home battered and abused. On the fourth documented time of abuse...and I'm documenting through my pediatrician...the abuse was so bad that I called the Police Department. (Bonnie Weninger, Milwaukee, WI)

We had an aide who was verbally and emotionally abusive. I tried to correct this by going and speaking to the [school] people...What happened? It blew up in my face. As a result, we had a principal who acted as judge, jury and executioner. Within five minutes, my grandson was suspended for five days, booted out of the district. (Claire Grandora, Albuquerque, NM)

Recommendations: Zero Reject

In order to ensure that IDEA's provisions prohibiting the exclusion of students from education based on the apparent or presumed nature or severity of their disabilities are more effectively implemented, the Federal government should implement the following recommendations:

1. Require State and local government entities such as public schools to be accessible to people with disabilities.

2. Improve and expand the process of providing information to *all* parents regarding their rights to access needed special education and related services regardless of the nature or severity of their children's special needs.

3. Clarify and strengthen the requirement that, except in rare instances of imminent danger to self or others, students with disabilities cannot be excluded or removed from school unless an individualized determination is made that their behavior is *not* related to their disability.

ASSESSMENT FOR ELIGIBILITY AND NONDISCRIMINATORY EVALUATION

Statement of Law

Through IDEA, Congress intended to facilitate the assessment of students in a manner that accurately reflects students' strengths and needs and then determines the need for special education. To that end, IDEA requires States to establish procedures to assure that testing and evaluation procedures and materials are not racially or culturally discriminatory. Thus, tests must be administered in a child's native language or mode of communication.

Furthermore, no single procedure may be used as the sole criterion for placement of a child in special education (20 U.S.C. Sec. 1412(5)c)). Regulations require that complete evaluations be conducted before a child is placed in special education (34 C.F.R. Sec. 300.531). Evaluations must be conducted by multidisciplinary teams which include a teacher or specialist in the possible area of disability (34 C.F.R. Sec. 300.532). In addition, students placed in special education must be reevaluated every three years, or more frequently if conditions warrant, or if the child's parent or teacher requests reevaluation. (34 C.F.R. Sec. 300.534).

Because of continued concern over the discriminatory evaluation and placement of minority students in special education, when it amended the IDEA in 1990 (20 U.S.C. Sec. 1409), Congress required the U.S. Department of Education to conduct or fund

studies to examine the overrepresentation of minority students in special education . Furthermore, applicants for grants from the Department of Education were required to show how they would address the needs of minority students with disabilities. The amendments also required discretionary programs to make greater efforts to prevent the mislabeling of students in special education. (20 U.S.C. Sec. 1409(j)(1)(B)).

Major themes in the testimony regarding assessment for eligibility and the nondiscriminatory evaluation provisions of IDEA pertained to the following issues:

- ◆ Problems with labeling children, including misdiagnosis and mislabeling;
- ◆ Tests being administered in a student's native language and mode of communication, valid for the purposes for which they are used;
- ◆ Overrepresentation of minorities in special education;
- ◆ Lack of clarity in assessment criteria;
- ◆ Parent participation in evaluation;
- ◆ Independent evaluations;
- ◆ Timeliness of evaluations, including the preassessment process;
- ◆ Minimum competency testing; and
- ◆ Creation of new categories.

Each of these areas will be briefly described below.

Problems with Labeling Children

In order to receive special education, students are required to undergo evaluations. These evaluations often result in the assignment of a disability labels to students, based on categorical listings of disability types ("mental retardation", "severe emotional disturbance", etc.). As a consequence, the expectations of parents, professionals, and sometimes the students themselves are altered, often negatively. In many school districts, an automatic equation has developed between the assignment of a disability label, the assumption that this label is, essentially, life-defining, the lowering of expectations, and the placement of students with similar labels with other students "of their own kind." Witnesses objected to this process:

Parents feel that it is important for children to be looked at as a total child, not just as a label. (Beverly Roberts, Charlotte, NC)

I would like to see absolutely no labeling of students....If there is an educational need, there is an educational need, just do it. It doesn't matter what the child's label is. (Edris Klucher, Albuquerque, NM)

After 20 years of successful implementation of a non-categorical system of special education in Massachusetts, we wholeheartedly support such an approach. It facilitates meaningful inclusion in regular classrooms, and it does reduce stigma. It almost forces reliance on individualized planning, a true IEP. It also recognizes that children differ more within categories than between categories and that their educational needs are often not label-linked. However, it is not necessary to change Part B in order to move to a non-categorical system. (Martha Ziegler, Boston, MA)

The stakes for parents and children involved in the special education evaluation process are high. Parents do not like the labels and "prophecies" of their child's future that come with evaluations for special education:

My young son...must learn, build his own self esteem, and learn his valuable role in society. He doesn't need to be singled out by receiving a label and all the self-fulfilling prophecies that attach themselves to that label...So please advocate the reauthorization for changes that will stop the identification, segregation, and isolation of students with disabilities. (Fran Maluri, Anchorage, AK)

One family spoke of their efforts to keep their adopted son's disability hidden from the school, even though they have adequate documentation for the child to receive special education services:

My family is doing whatever we can to keep our adopted son's disability hidden from the school, knowing that once the disability is labeled...the expectations that will arise will not at all be positive. (Witness,⁵ Anchorage, AK).

Typically, a child with special education needs begins school in a system which places labels on the child at a very young age. The child may fall into a label or category in which it is predetermined that their only goal in life is vocational:

I was told that Jon would do well at becoming a janitor or a handy man and not to expect too much from him. (Beth Gage, Philadelphia, PA)

While vocational programming may eventually be determined to be a proper course for individual students, it may not be the appropriate goal for other students (David Levy, Anchorage, AK). Such predetermination of program options based on the presumed nature or severity of a disability is in violation of the individualized assessment and programming provisions of IDEA.

⁵ Name withheld to protect confidentiality.

Parents report that mislabeling and misdiagnosis have direct and adverse effects on the education of their children. One parent asserted that the label of "severely emotionally disturbed" had to be contested and removed before her child could receive an appropriate education (Tammy Stuck, Denver, CO). For this reason, she recommended that the State educational agencies be required to provide a full explanation when assigning this label to children. Another parent voiced her disaffection with the requirement that children have a categorical label at all:

We are tired of having our children labeled just for services. Give our children a chance to prove themselves. (Josie Torrez, Des Moines, IA)

However, another witness cautioned that school districts might interpret a reduced emphasis on categorically driven services to mean that they no longer need to provide necessary supports and services to students with special needs:

We also have concerns about proposed changes in disability categories which may result in denial of services for some students with disabilities or may result in dumping them in regular classes without appropriate support services. (Charlotte Des Jardins, Milwaukee, WI)

Another parent agreed that the special education labeling process is very stigmatizing to children and families, but was not in favor of disregarding labels altogether. She made the point that without labels, schools might not be accountable for the services they provide (Sara Gonzales, Albuquerque, NM). However, another witness stated the following:

We also need to break down the barriers at the national level that encourage school districts to segregate students, to identify and label students and place them in

separate programs such as Chapter I, bilingual, migrant ed, Indian ed, and special ed. (Robyn Rehmann, Anchorage, AK)

According to Ms. Raymond, the requirement that students be labelled in order to receive assistance across a variety of Federal programs results in many school districts placing 40% of their students in one category or another.

Given the complex nature of this issue and the fact that all of the above-mentioned programs are covered under differing Federal statutes, it is difficult to envision a single satisfactory solution. However, one witness made the following recommendation with regard to special education programs:

Since most States operate funding systems based on categorical labels, these systems will require complete overhaul, often a very complex and controversial process. It would probably not be helpful for the Federal law to require such a change. Since labeling is not useful to children and, in fact, is often harmful to them, the Federal Department of Education should encourage States to move away from it voluntarily. Rather than move to change Part B at this time, perhaps OSEP could fund a study to determine the feasibility of such a change in the future. (Martha Ziegler, Boston, MA)

Native Language and Mode of Communication

Multi-cultural families often seem less aware of their rights in special education and also don't get the services they may be entitled to, often because of language barriers. (Elissa Gershon, Berkeley, CA)

I would be called a person of a minority, and I, myself, or my family do not consider ourselves minor in any way. I believe we need to use words such as "diverse-/cultural-/linguistic-ability backgrounds," rather than the word "minority," and I ask that IDEA move away from some of those kinds of labels. (Diego Gallegos, Albuquerque, NM)

Special education is sometimes perceived as being a kind of white middle class issue. I just want to point out and underscore what a number of parents here have said tonight. The kind of resources it takes for a family to

get appropriate programs and services is so totally overwhelming in terms of time, energy, money, and skills, that it's really not surprising that the people who tend to be the most visible are the parents with the most resources.
(Diane Lipton, Berkeley, CA)

Culturally sensitive evaluation, particularly testing in the student's native language, is a major issue. In the evaluation of students from different ethnic, racial, or linguistic backgrounds, persons on the evaluation team often do not speak the child's language and do not share the child's cultural or racial background.

Evaluation and assessment teams often do not include minorities, particularly Hispanics and African-Americans. Rarely is there an evaluation team member who speaks the native language of a family. Often, translation is done—if it is done—by people who are not familiar with the family. (Tom Patrick, Denver, CO)

In cases where translators are used, the outcome of the evaluation process is still dubious. Translations of tests are criticized, and persons who are translating for the evaluator are often unfamiliar with students and their families. In one instance, a Native American child was unresponsive until his mother was allowed to translate the test into his native language (Tom Patrick, Denver, CO). In one school district described in the testimony, evaluations could be conducted in the child's native language (Spanish, in this case), but only if a translator was available. Translation and adaptation of standardized testing procedures are inadequate solutions to the cultural differences found in many testing situations across the country.

Certain Latins...don't know the language. We don't know English. We should not be frightened of professionals. We should be proud, and we should demand the best for our children even though it may be in Spanish.
(Reina Fernandez, New York, NY)

Though school psychologists attempt to adapt their testing protocols to meet the needs of Native American children, this translation has not always been successful. (DuWyne Geist, Denver, CO)

One parent spoke for many when he explained the way parents perceive the school's treatment of them as minority persons:

Other concerns families raise is the lack of respect for individual differences, values and preferences. When parents are asked if evaluations are sensitive to cultural values and linguistic backgrounds, they often say, "No." (Tom Patrick, Denver, CO)

For students with certain disabilities, even tests in their native language may be inappropriate to the purpose for which they are used, because they are not consistent with the child's manner of communication. For example, standardized tests may be particularly inappropriate for students with autism:

I believe strongly that the Stanford-Binet, Bender, and similar psychological tests are inappropriate for children like [my son]. The tests do not adequately measure our children's intelligence because often the students do not understand what is required of them, even though they may have the knowledge or ability to complete the task. Consequently, they end up with a poor showing and low scores....New tests need to be developed. They should be more practical, less academic, and administered in a manner consistent with the methods of communication that the autistic and other members of our mentally challenged population employ. (Marjorie Gouldbourne, New York, NY)

Where schools and States have turned away from strong reliance on traditional standardized tests for the purposes of student evaluation, parents have supported that change. Curriculum-based testing is one example of an alternative (and preferred) assessment method, because it leads to educational strategies and objectives, rather than simply identification (Judy Plzak, Philadelphia, PA). One parent with long experience in special education commented that in his state (Montana), the assessment situation is

certainly better than it was 50 years ago. In general, there is less reliance on IQ tests and more reliance on classroom observation, local norms, and evaluation of classroom performance (DuWyne Geist, Denver, CO).

Other parents criticized testing procedures that are stigmatizing because of their dissimilarity to those used by general education. They strongly questioned the usefulness of tests that turn their children into *little white rats* (Diane Cox, Denver, CO), and recommended that standards-based educational assessments would be more appropriate for their children.

Why do we still have to be different? Why are our children tested every time they turn around: daily, weekly, monthly, yearly, triennially, informally, formally. [It] makes no difference...some testing is okay, but a lot of it is just purely obnoxious. It should look like standards-based education for the other children. (Diane Cox, Denver, CO)

I wrote the [school district] telling them that Casey would need to take the springtime standardized eighth grade test in an untimed manner and in a quiet place, per his doctor's orders....They refused to modify the test. Even after I checked with the State Special Ed Department (which said, of course, it could be modified)...I was told no....We decided not to subject Casey to an inappropriate testing situation. (Judy Bonnell, Albuquerque, NM)

Parents also complained that proper safeguards are not in place to prevent evaluations without accommodation. For instance, parents had to take a child with dyslexia outside of the school system for private testing (Jill Rigsbee, Charlotte, NC). In another situation, an evaluation was performed on a legally blind child using a visual test. Because of this obviously discriminatory test, the child was labeled mentally retarded (Jane Hasty, Charlotte, NC). Other parents stated that they wanted to have

their child independently evaluated because the school was conducting tests on visually impaired students without proper accommodation (Robin Ann Tracy, Boston, MA). Several parents requested sanctions and fines on school districts who blatantly misevaluate children for special education (Robin Ann Tracy, Boston, MA; Judy Bonnell, Albuquerque, NM).

On a more positive note, witnesses testified that assessments related to IDEA-sponsored early intervention programs (birth to three) on some Native American reservations were working and that funding for these programs should continue. For example, when an early intervention program first started at the Laguna Pueblo (NM), community members were skeptical about the program. However, the fact that the early intervention professional was also a Native American helped to gain the trust of the parents:

I felt that the families were a little bit reluctant. [Even though] I'm a member of their own tribe, that they still considered me an intruder of some type, because a lot of other times when programs came in, they felt that there were too many people hounding them or hovering over them and wanting them to do this and do that, but as I explained to them, I'm also the parent of a child with disabilities, and that made it a little bit easier. I share their culture and beliefs, and I encourage them to use traditional medicines, never doubting that, and that always comes first, but at the same time, getting them to believe that in reality, too, there is something different. And that's how I've gained a lot of the parent's trust. I'm hoping IDEA will continue, so that our children will continue to benefit from these services and the programs...that more can be established, to give the tribes an opportunity to establish more of these programs for them. (Norberta Sarracino, Albuquerque, NM)

On the subject of cultural and linguistic sensitivity, witnesses made the following suggestions:

- ◆ IDEA can discourage discrimination and encourage access to needed services for multi-cultural populations by requiring evaluations to be done in the student's primary language, providing interpreters, and providing translation services. (Elissa Gershon, Berkeley, CA)
- ◆ IDEA should require coordination between bilingual general education programs and special education programs so that access to these services is the same. (Elissa Gershon, Berkeley, CA)
- ◆ IDEA should require outreach programs directed at minority communities and families to educate parents about their children's rights. (Elissa Gershon, Berkeley, CA)
- ◆ IDEA should strengthen its parental notification requirements to ensure that parents are given advance notice of their right to participate in their child's education process. (Jeannie Manuelito, Albuquerque, NM)
- ◆ IDEA should require non-discrimination training for school personnel, including the unique communications and learning styles of children and their parents who are from diverse backgrounds, to ensure that children from varying cultural and linguistic backgrounds are not subject to discrimination. (Jeannie Manuelito, Albuquerque, NM)
- ◆ Diversity among special education professionals can be improved if funds continue to be targeted at minority institutions for the purpose of recruiting and preparing minority college students to enter the special education field. Moreover, institutions of higher learning in which 25% of the student body is a part of a minority population should be considered minority institutions which qualify for these funds. This 25% figure should be retained and not increased. (Deborah Doherty Smith, Albuquerque, NM)
- ◆ The Part H requirement that the Individualized Family Service Plan (IFSP) meeting be held within 45 days of the initial special education referral should be lengthened. This does not allow enough time for a child living a rural area to be evaluated because the child must come to a city or the evaluation team must go to the rural area. Moreover, it is not enough time for parents of diverse cultures to process the need for special education services. (Susan Jones, Anchorage, AK)

- ◆ The funding formula for early intervention should also take into account and increase the funds for a particular State depending on the cultural diversity of the population, geographical dispersion of the population, and the number of children living in poverty, because it is more expensive to provide services to these populations. (Susan Jones, Anchorage, AK)

Overrepresentation of Minorities in Special Education

The overrepresentation of minority students in special education also was discussed by witnesses at the hearings. One witness, who has extensive experience in this area through her personal experience as a parent of an adult with disabilities and her work at a parent training center, explained that cultural differences between students and school staff may account for the troublesome statistics.

Sometimes black students tend to be more verbal, tend to be a little more touching, a little more jostling. I think some times because the majority of the professionals who work with these students in school are majority persons...there is not anybody in that culture to even help problem solve, to help them come up with creative answers...

There are many reasons for this, and if knew all the answers, I would be in Washington getting a lot of money. But some of it has to do with the ability of parents to understand what rights they have to keep their children out of special education. (Virginia Richardson, Des Moines, IA)

Other witnesses echoed this sentiment:

I have been in special ed for 20 years. I believe that children of diverse backgrounds, especially children from different linguistic backgrounds, are way over-identified in special ed. It's an area of concern for us. It's an area we're working in. It's also one that, in the past, there has not been enough attention to, in my opinion. (Diego Gallegos, Albuquerque, NM)

We have to eliminate all the bias we now still see for referral of students from minority backgrounds. (Fran Maiuri, Anchorage, AK)

Over-identification of disabilities in minority children is a known flaw in the cultural identification techniques, which fail to factor in cultural differences. The over-identification has led to an inordinate percentage of children of color who are placed in special education programs. Today these programs essentially segregate them from the full academic and cultural experience. The impact of minority status, cultural factors, and level of severity of disability must be adequately addressed in order to effectively meet the needs of children. (Paul Spooner, Boston, MA)

While overrepresentation is a problem, underrepresentation of minorities can also be a problem. Minority children are often on long waiting lists to be assessed for special education, especially if their parents do not use English as their primary language. The parents often do not have access to or understand information about how their children are doing in school and their children's rights to special education (Diane Lipton, Berkeley, CA). Underrepresentation of minorities in special education also occurs because school districts cannot afford to engage in the outreach activities required by the IDEA (Birgit Schweingruber, Berkeley, CA).

Witnesses made the following suggestions for addressing the overidentification (and sometimes, underidentification) of students from diverse backgrounds in special education:

- ◆ Other States could learn a lesson from Alaska, where a majority of students are from mixed or non-English homes and are economically, experientially, and culturally out of the mainstream; yet Alaskan school districts still have low special education child counts. This is not because of the underidentification of students who need special education services but rather because the regular education program accommodates a wide range of student diversity and because disability identification proceedings respect that students' cultures, languages, and life experiences are different from those assumed by our Anglo-based traditional measures and procedures. (Christopher Robinson, Anchorage, AK)

- ◆ Special education should be restructured from its current quasi-medical model built upon supposedly empirical categorical labeling to greater education services for everyone. Special education can prevent the overidentification of students by discontinuing evaluation practices that rely upon normative, time-limited extractions of data in unnatural settings. The identification of students for special education should utilize functional assessments, diagnostic teaching strategies, evaluations which take place over time in natural environments, as well as observational and clinical impressions of each student's ability. (Christopher Robinson, Anchorage, AK).

Parent Participation in Evaluations

Families complain of evaluations that are done in places that...their child is unfamiliar [with], rather than in their home or familiar child care settings. The time of the evaluation rarely coincides with a child's, quote, "good period," or at a time and place which is convenient for both parents to participate. (Tom Patrick, Denver, CO)

Sometimes a "behavioral impairment" is the only label that a parent will ever get. I had one psychologist tell a parent, "Well, you don't need to know what's wrong with your child. You just need to do what we tell you to." "Seriously," I said, "What is this child's diagnosis?" And this psychologist sat there and talked about the child. It was very obvious he had a major mental illness, and he refused to tell the parent what it was, [saying] that he was only "behaviorally impaired." (Cindy Sirois, Boston, MA)

All in all, most parents reluctantly accept the *burdensome...but necessary* (Deb Sherer, Denver, CO) evaluation process, but they wish for something better. Currently, without evaluation, students with disabilities could not get the services they need, and parents generally believe that good assessment is key in getting an appropriate education. However, along with the concerns noted above, many parents believe they were not valued as equal participants in the evaluation process (Tom Patrick, Denver, CO). Parents and persons with disabilities sharply criticized the assumed predictive

results of superficial testing procedures compared with the day-to-day experience of living with, or as, a person with a disability:

I can't tell you how many IQ tests and psychological evaluations I went through every year with someone that I had never met before. In an hour, they were going to decide my psychological status, my IQ, and my abilities, and that was used for my educational plan. (Julie Farrar, Denver, CO)

Over and over again, parents testified about being shut out of the assessment and evaluation process. One barrier to their participation in the evaluation process is the use of technical or other language unfamiliar to ordinary persons. One parent explained that as a Spanish-speaking person, she listened to the results of an evaluation, not understanding anything that was said (Reina Fernandez, New York, NY).

Witnesses made the following suggestions to improve parent and student participation in the assessment process:

- ◆ Provide parents with a draft assessment that invites their comments and review prior to staffings and IEP meetings. (Tom Patrick, Denver, CO)
- ◆ Conduct evaluations in familiar environments, like the family home or child care situations. (Karen Fernandez, New York, NY)
- * Interview the child and family at home, where the needs of the entire family can be assessed, including needs for related services, like parenting assistance, or family, individual, or sibling counseling. (Karen Fernandez, New York, NY)
- * Send information on developmental milestones home with babies from the hospitals when they are born, emphasizing prevention and early identification. (Karen Fernandez, New York, NY)

Lack of Clarity in Assessment Criteria

Parents who were particularly concerned about children with attention deficit disorder (ADD) requested that guidance regarding the identification and testing of students with ADD be placed in the law. One parent discussed her difficulties in getting her child evaluated:

Our system will not even test for ADD, although the law requires it. Our system will not implement even the most rudimentary classroom tactics to deal with the disorder. They refuse to discuss it, test for it, and deal with it in any way. I do not understand how they manage to completely ignore a disorder that the law has mandated will be addressed. (Judy Bonnell, Albuquerque, NM)

Another parent characterized ADD as a disability that affects children in many aspects of their lives. She asked for a broader interpretation of the term "adverse educational impact" which is used in the determination of eligibility for special education:

In most States, "adverse educational impact" is interpreted as meaning "documented academic failure." Only then are aid and support offered....It shouldn't rely solely on eligibility criteria that requires documented academic failure... "adverse educational impact" [should] be assessed on the basis of the student's overall academic, behavioral, and social functioning. (Julie Doy, Des Moines, IA)

Alternately, another parent suggested that attention deficit disorder might be considered under the "Other Health Impaired" category (Barbara Duvall, Berkeley, CA).

In another area, students with learning disabilities who are also gifted, while not yet failing academically, often suffer great personal frustration due to their disability. Witnesses concerned with these students requested greater guidance and assistance:

I know there are children who have learning disabilities, but for various reasons did not qualify for services with traditional testing. I know my child and others did not qualify for help based on the testing that was being done, but are in need of services. Why can't we use more than one option for testing our children? We are all unique, even in our disabilities. (Lynette Jensen, Des Moines, IA)

Sometimes I feel that children with a learning disability are considered children of a lesser God or a lesser disability...It's an invisible kind of disability, and what happens is people think, because he looks so-called "normal," that he can do other things that other children can do. (Karen McGinley, Boston, MA)

Because learning disabilities are a hidden handicap, it's easier not to provide them with the services that they need even when they do have a diagnosis. For a student who's got attention deficit disorder and a specific learning disability in addition to that, it's easier to just give them Ritalin and not to give them that educational experience. For the student who comes from a deprived home, it's easier to blame their learning problems on the deprived home than it would be if they were in a wheelchair. (Dave Gordon, Boston, MA)

Independent Evaluations

Typically an IEP will state the method of evaluation is "teacher observation," which, although it is very, very valuable, should only be one piece of how the program is evaluated. (Laura Glomb, Boston, MA)

Our brief involvement with the public school system involved their initial evaluation that they were going to use to devise his educational plan and place him. It took place in a 4-by-7 room with Peter and myself, a teacher that was not a certified special education teacher, a physical therapist, and an occupational therapist. It took a grand total of 45 minutes, during which there was no hands-on work with Peter. There were generic questions directed at me...This team seemed to feel that, through this evaluation, they would be able to write an IEP for Peter and recommend appropriate placement...That concerned me greatly. (Melissa Constantine, Boston, MA)

Parents often turn to independent evaluations when their evaluation requests are not honored by districts or when they are seeking more acceptable alternatives to the programmatic options offered by a school district. These parents strongly support

provisions for independent evaluations as a tool they need to advocate for appropriate educational programs for their children:

Outside evaluations must be easier to obtain to avoid bias and to obtain expertise for specific disability categories. (Jan Serak, Milwaukee, WI)

Parents reported on using outside experts to help them get educational accommodations and services they needed. However, many parents testified that their attempts to negotiate students' programs through using independent evaluations were met with resistance from school districts. One parent, who brought an independent evaluator to meet with school staff, was told that the staff would only be *in a listening mode* (Greg Omori, Des Moines, IA).

We invited one of the evaluators, who had a Ph.D., at our expense to come to Dubuque to observe Alex in a school setting...We were told later that the independent evaluation was considered, when honestly, it was ignored. (Greg Omori, Des Moines, IA)

Timeliness of Evaluations

There is no real standardized way of accepting the child into special education or getting him the right of amount of hours with the right amount of services. I think [teachers] feel like it's a generic kind of system....The regular education teacher's going to say, "Oh well, look, he walks funny. He doesn't walk like I do — Adaptive P.E." That's put on the IEP and the kid's in. Now I have to go and I have to start looking for ten pounds of paperwork because the kid was never assessed, never referred, and the parents were never informed. (Sam Reder, Anchorage, AK)

The evaluation process is the gateway to getting special education services. Several parents testified that the entry of their children into special education services was delayed by several factors. First, pediatricians are sometimes unresponsive to

parental concerns about their child's development, or they wait to see if any perceived problems will resolve themselves through the normal development process. Also, a required "preassessment process" after a problem is noted at school can cause delays, or even denial of special education services. As one parent stated, when it comes to initial evaluation, *time is of the essence* (Josie Torrez, Des Moines, IA).

One witness recounted her plight and that of her child, Jenny, in trying to obtain a timely evaluation for services when they were homeless. An interpreter read her statement and described her struggle as follows:

Juliana went through a great deal. She had no services, was homeless with her child. She spent a lot of cold days, slept in someone's house on the floor with her child. The child had no wheelchair...Jenny had never been to school in her life. She is multiply handicapped, is blind, has cerebral palsy, and some other disabilities. It took a year from the request for evaluation to placement of this child [in special education]. (Juliana Rosario, New York, NY)

Another child was hospitalized several times for psychiatric problems but was not evaluated for a learning disability by the public school system until eight years later (Cindy Sirois, Boston, MA). One witness testified that the state of Tennessee has 4,373 children who have been referred for evaluation but have never been assessed (Pam Zacha, Charlotte, NC).

Some parents thought student assessment teams (often employed in the pre-assessment process) should be used more, with special education professionals involved in these teams. However, others viewed the student assessment team as a barrier to

getting needed services. These parents were also concerned about protecting their children's rights while in the preassessment and evaluation process. Numerous parents suggested that when a school system does not have adequate personnel to perform evaluations in a timely manner, it should be required to pay for private or independent evaluations.

Minimum Competency Testing

I asked how they tested special ed students. I was told that students sometimes take standardized tests just to have the experience, but the test serves no real purpose. How demeaning! (Judy Bonnell, Albuquerque, NM)

I am the only Down syndrome student that has ever passed a placement test at TVI [Technical Vocational Institute]. (Nannie Marie Sanchez, Albuquerque, NM)

The educational movement toward statewide assessments, often conceived and referred to as "minimum competency testing," was discussed in relationship to how students with special needs are included in this process. This is a complex issue, and not directly related to evaluation for the purposes of identification. However, it is indirectly related to identification, in that testimony indicated that teachers were under pressure to identify low-scoring students as "special education" students, thereby eliminating their test score from their class total (Liz Hesse, Denver, CO). Thus, in this instance, minimum competency testing can cause increased referrals to special education.

Parents also discussed the effects of minimum competency tests and testing procedures on their children. Students with special education needs may require adaptations to take such tests, and there is a lack of clarity about whether these adaptations invalidate the tests themselves. Parents recommended that students with special education needs be included in the testing procedures, with needed adaptations, unless their IEP team decided that they should be exempt. As one parent, a former recipient of special education, stated:

Special education referral should never automatically exclude a student from standard expectancies. (Liz Hesse, Denver, CO)

Creation of New Disability Categories

Several witnesses advocated for the creation of new disability categories or for changing current definitions of existing categories in order to accommodate various disabilities.

Neurobiological Disorders

I would like to have...a category of neurobiological disorders...that encompasses the children who have schizophrenia, bipolar disorders, and attention deficit hyperactivity. (Delfy Roach, Albuquerque, NM)

Many parents advocated for the creation of a separate category for neurobiological disorders (NBDs). One parent spoke about the problems of fitting neurobiological disorders within existing disability categories:

I would like to speak about these children that we like to call children with neurobiological disorders. Our children are very stigmatized when they're served under the category of SED...As their parents, many times, when we go to try to work with the schools, our advice and our input is discounted because we're seen as the cause of their disturbance...The families that we

represent would like to see a change in the SED category, to truly talk about what's going on in the brains and central nervous systems of children with special learning needs...because research has shown that many of the behaviors and the learning needs of children are generated because of...the brain dysfunction, and so we would like to see that reflected in the law.
(Sara Gonzales, Albuquerque, NM)

Parents recounted a number of bad experiences that occurred because their children with neurobiological disorders were placed in inappropriate special education categories. One woman's son had a neurobiological disorder and was placed in the category of "seriously emotionally disturbed" for five years. This classification did not fit his needs, but it was the only way he could get services for him to stay in school:

"Seriously emotionally/behaviorally disordered" does not appropriately address the issues that our children have, and I think we do a great injustice to these kids. Too much time is spent on trying to cure the illness through behavior modification, through behavior management, and what happens is our kids get very frustrated, they get treated inappropriately, academics suffer, and self-esteem suffers. (Delfy Roach, Albuquerque, NM)

One parent had a daughter with a neurobiological disorder who was labeled as "seriously emotionally disturbed" for eight years before she had brain surgery which confirmed she had a neurobiological disorder. She is now classified as "other health impaired: neurobiological disorder" (Rebecca Viers, Albuquerque, NM).

The regulations interpreting IDEA now define SED as an inability to learn that cannot be explained by intellectual, sensory, or health factors. Clearly, children who suffer from NBD have an illness that explains their episodic inability to learn. Our recommendation that a separate category for NBD children be established would place neurobiological disorders...on a par with specific learning disabilities, autism, and traumatic brain injury, each of which the current law recognizes as a category separate from SED.
(Rebecca Viers, Albuquerque, NM)

One parent testified that her son, who had a neurobiological disorder, was classified as having communication and behavior disorders. The behavior disorder program he was placed in used physical restraints, which only made her son become aggressive and made his neurobiological disorder more problematic (Betty Cope, Albuquerque, NM). Finally, one woman reported that her son ran away from school and wrote a suicide note due to the fact that he was not receiving the proper services for his neurobiological disorder (Joy Angelino, Albuquerque, NM).

I beg of you to consider a category for children with neurobiological illnesses, separate from the category of seriously emotionally disturbed. (Joy Angelino, Albuquerque, NM)

Emotional Disability and Mental Illness

I feel that children with major mental illness should come under the category of "Other Health Impaired." (Cindy Sirois, Boston, MA)

A school provides services to adolescents receiving treatment (often drug and alcohol treatment) in a locked unit, [in a] residential hospital. When the school tries to get public funds to help provide services for the children, it is problematic because the children do not fit the existing parameters of what a disability is...Mental illness should be made a disability under IDEA and parameters set for the funding of children who suffer from mental illness. (Patrick Cabellero, Albuquerque, NM)

The National Mental Health and Special Education Coalition is suggesting that the term "seriously emotionally disabled" be changed to "behaviorally/emotionally disabled." A new category dealing specifically with brain disorders and brain functioning should be implemented. (Rebecca Viers, Albuquerque, NM)

One witness described recurring situations where children leave psychiatric treatment facilities and then attempt to access special education services through schools. Often, such children have undergone psychiatric evaluations, but the

evaluations use medical terminology and cannot be used to certify them as "seriously emotionally disturbed" in order to qualify them for special education services. Instead, these children must then undergo evaluations by psychologists who will use "proper" terminology so that they may qualify for special education.

Let's say that I just recently have a child who came back from residential psychiatric treatment. We have a psychiatric evaluation that we cannot use to certify him under the Federal definition for SED because they use medical terminology... We're having to have a school... psychologist go out there to do the evaluation in order to get the child certified. A new definition of SED should be promulgated which is consistent with the medical terminology used by residential psychiatric treatment centers. (Pamela Carter Simpson, Anchorage, AK)

Summary of Assessment for Eligibility and Nondiscriminatory Evaluation Issues

The evaluation process continues to have problems that directly impact on the implementation of the law and the regulations. Parents have many and varied concerns about the process and their empowerment within the process, but parents also envision evaluation as an integral part of offering special education services. One parent, who works for a parent training center, was particularly eloquent when she linked evaluation to the larger educational process:

Evaluation is a beginning, not an end. The evaluation of each goal is the beginning of the next goal. Parents see the growth and development of their children and understand that accomplishment of one skill leads to the building of the next. Teachers, too, need to see the un-endingness of their task of teaching. Evaluation and reassessment of skills being taught continuously branch out to more and more skills in a never-ending process of lifelong learning. Never should a child be placed on hold awaiting the next IEP or three-year evaluation before allowing the opportunity to build on the skills achieved. (Nina Baker, Des Moines, IA)

Evaluation and education are a part of a child's life, key to accessing support and having opportunities to learn, have friends, and enjoy life within their families and school communities.

Recommendations: Assessment for Eligibility and Nondiscriminatory Evaluation

In order to improve and strengthen the assessment and nondiscriminatory evaluation provisions of IDEA, the Federal government should implement the following recommendations:

1. Change the orientation of special education assessment in general from its current quasi-medical model built upon categorical labeling to more individually responsive and relevant assessment measures. Special education can prevent the overidentification of students by discontinuing the use of evaluation practices that rely upon time-limited data gathered in unnatural settings, which often do not take into account a student's cultural or linguistic background. The identification of students for special education should at least be expanded to utilize functional assessments, diagnostic teaching strategies, evaluations which take place over time in natural environments, and observational and clinical impressions of students' strengths and needs.
2. Encourage State and local education agencies the flexibility to adopt a noncategorical approach to serving students with special needs. This would change the focus of evaluation and assessment efforts from discovering and fitting a student's learning needs into a predetermined list of categories to a focus on determining what types of assistance the student needs and how this assistance might best be delivered.
3. If a noncategorical approach to eligibility is not adopted, students with neurobiological disorders should be eligible to receive special education and related services under the "other health impaired" category, if the assessment team determines that the student has special learning needs.
4. Enforce the requirements that evaluations be done in a student's primary language and be consistent with the student's primary mode of communication (e.g., sign language), that testing take into account the nature of the student's disability (e.g., blindness), that interpreters and translation services are available, and that the student's cultural background is taken into account.

5. IDEA should require coordination between bilingual general education programs and special education programs so that students may avail themselves of the full array of services offered under both of these programs.
6. IDEA should strengthen its parental notification requirements to ensure that parents are given advance notice of their right to participate in their child's education process. This should be accompanied by establishing or strengthening outreach programs directed at minority communities.
7. IDEA should require nondiscrimination training for school assessment personnel to ensure that children from varying cultural and linguistic backgrounds are not subject to discrimination.
8. Fairness in evaluation and placement will be improved by continued support of diversity among special education professionals made possible through funding targeted at minority institutions for the purpose of recruiting and preparing minority college students to enter the special education field.
9. Parents should be given the authority to extend the current 45-day time limit for the completion of an Individualized Family Service Plan (IFSP) under Part H in order to accommodate families living in rural areas and to ensure that families from diverse cultures fully understand the process and its intended results.
10. The criteria for allowing students with attention deficit disorders, learning disabilities, and neurobiological disorders to receive special education and related services should be based on the student's overall academic, behavioral, and social profile, rather than solely on documented academic failure.
11. Unless there are specific parental or student waiver statements on a student's IEP, it should be presumed that all students with disabilities should be included in the overall school assessment and testing program.

APPROPRIATE EDUCATION

Statement of Law

An appropriate education is one that (1) is specially designed to meet a student's needs, (2) benefits the student, (3) is based on an appropriate, nondiscriminatory evaluation, and (4) is described in the student's individualized education program (IEP). The student's IEP must state the student's present level of educational performance, short term objectives, and one-year goals, as well as the services the student is to receive (including related services), the extent to which the student will be able to participate in regular education programs, and criteria and procedures for annually determining whether the objectives are being achieved (20 U.S.C. Secs. 1400(b)(2) and (3), 1401(16), (17), (18), and (20)).

By the time a student turns 16, the student's IEP must describe transition services (20 U.S.C. Sec. 1401(a)(19) and (20)). When an infant or toddler is receiving early intervention services, there must be an individualized family service plan (IFSP) that describes the services to be provided to the child and the family (20 U.S.C. Sec. 1477).

Appropriate Education Generally

Testimony regarding the issue of appropriate education was mixed: Some witnesses testified that they believed that they or their children had received an

appropriate education; others were less positive. In testimony regarding her son with cerebral palsy, one mother expressed her overall satisfaction with the process:

A key to Michael's success has been the teamwork of all the educational professionals involved in Michael's program. The IEP process has allowed us to carefully plan and individually tailor Michael's educational goals and objectives. (Susan Tachau, Philadelphia, PA)

A former special education student felt differently:

I was viewed by some educators as "different." I felt like anyone else in the room, because of who I am, and I am proud of my disability. My family has always had to fight every step of the way so that I could take classes. Professionals in the schools and in this community have always placed limits on my capability and have not given me opportunities. They laugh at my needs. In our school, we have some teachers who are concerned and want us to walk away with skills to become productive citizens in our world community, but there are teachers who have made fun of me in front of my peers because I am disabled. (Nannie Marie Sanchez, Albuquerque, NM)

Some parents testified that the IEP allowed their child to be successful in school. In one situation, the IEP responded to a student's challenging behaviors by specifically explaining how to redirect the child's self-abusive behavior, thus enabling the student to manage his own behavior more effectively. Other parents and students testified that as a result of their IEPs, they found success later in college and even carried this individualized approach over to their college education. However, in spite of testimony of this sort, there was a great deal more testimony about problems with IEPs.

Individualized Education Programs (IEPs)

Parent and Student Involvement and the IEP Meeting

In regard to the IEP process itself, I wish it stood for "Individual Encouragement to Parents." If we could change it, I would change it. In

many ways this public law has become our enemy. Educators are being consumed by accountability and the IEP process itself. This process is not a true process at all sometimes until due process...the reason being minimal parent involvement until it's too late. The IEP process is so labor intensive that it actually drives us away from the child instead of closer to the child. It has become a burden to our professionals. You may have five to eight professionals on a team and not one of those people really possesses a true trusting relationship with the parents. Not one sees the big picture of this child's life, because they are caught up in the accountability, they are caught up in time, which also becomes their enemy. (Kathy Davis, Des Moines, IA)

At every hearing site, witness after witness testified that the IEP process is extremely frustrating, often intimidating, and hardly ever conducive to making them feel that they were equal partners with professionals:

I believe parents come to the IEP meeting as an unequal partner. Our signature means only that we were present at the meeting. (Christi Murn, Milwaukee, WI)

Before you can educate a child, you have to educate their parents. A parent who knows little about their child's disability and even less of bureaucratic process involved in educating his child is at a serious disadvantage. (Lisa Reader, Albuquerque, NM)

Regarding IEPs, more often than not parents are presented with what is more or less a completed IEP at their planning placement team meeting...The goals and objectives are generally very, very, vague, nonspecific and often don't have an appropriate way to evaluate whether the child is making progress in his or her program. (Laura Glomb, Boston, MA)

Many parents stated that school officials did not respect their opinions and did not attempt to include them in developing their children's goals and objectives. One parent testified that she had to become *loud and obnoxious* in order to express her opinions at the IEP meeting and to get the services that she thought her child needed. Teachers often arrived at the IEP meeting with a completed IEP, causing the parents to

feel that their input was not important. Some parents did not receive notice of IEP meetings, nor did they receive copies of the completed IEP. Some IEP meetings were described as hostile. Parents felt intimidated because they did not know what to expect from the IEP meeting, their rights as parents under IDEA, or the technical language used by professionals.

Each year I speak frankly, clearly and in English that I feel Katie is not in an appropriate program. To quote, "We've tried our best Mrs. Reed," is what I always hear. Each year I put another candle on the cake, and when I blow out Katie's candles, I say, "Maybe this year, Katie, maybe this will be the year we have the right teachers, the right program and the right way to communicate with you"...In two days we'll light another candle on Katie's cake and another year will have gone by. I'll still make that same wish: that this year maybe things will change. (Catherine Reed, Boston, MA)

Parents know their children better than anyone, including teachers and other professionals, and their input should be respected, recognized, and utilized in developing their child's IEP.

Some of the witnesses were former students, and two of them commented on the IEP process as follows:

I got teachers that would not help me...I never went or was invited to my IEP meetings...No one ever told me about my disability. I don't really know what my disability is...Twelve years of special education should have prepared me for a life without so many unnecessary problems...with the education I should have had [as] my right under IDEA, things would be better for me and for my children. (Linda Melendez, New York, NY)

I think that special education has its particular poignance when kids are young and I think that often, children —and I don't care what kind of disability the child has, whether it is cognitive or physical— are not often asked what they want, and therefore, they are given a double message. They

are being told that they need not be asked what they want. (Lisa Janoff, Philadelphia, PA)

Witnesses suggested how the IEP process might be improved:

- ◆ Parents, together with the school's IEP team, need to establish an open line of communication regarding the parent's role in the process and the services available to the child.
- ◆ An administrator needs to solicit and collect input from the parents, other teachers, and therapists before the meeting and then identify areas of concern and disagreement, thereby enabling the meeting to run more smoothly.
- ◆ Concerns and problems could be alleviated through parent education about the IEP process, technical terminology, and parental rights under IDEA. Such an education program would inevitably enable parents to feel more control over their children's education and lessen the struggle with school professionals.

The IEP Itself

I've been to 57 IEP meetings. Not once, not ever once, did a school offer a regular class placement as a placement for a child. Beyond that, they never offered, never discussed, never considered what kinds of supports, modifications, options would be necessary for a child to succeed in a regular class environment. Children are placed within existing programs, they're placed categorically and/or into existing programs. (Laura Glomb, Boston, MA)

A major theme running through the testimony at every hearing site was that the IEP should be based on the child's individual needs and on high expectations for achievement:

The child's IEP should reflect the growth she needs to reach her highest potential. (Nina Baker, Des Moines, IA)

Children with disabilities must be ingrained with the idea that they deserve nothing less than to live, rather than merely to exist. (Bernadette Griffin, Philadelphia, PA)

I'm concerned that many times it's proven easier to find a volunteer or a teacher's aide to provide such skills as note-taking for blind and visually impaired individuals rather than teaching that student and providing that student with the appropriate technology to do that independently. (Brian Charleson, Boston, MA)

Some witnesses testified that the short-term goals and objectives of the IEP can serve as the benchmark of effective learning and teaching and that they are extremely important to focus the child's time and resources. Witnesses stated that these goals could be improved by using family strengths and values to develop the goals, ensuring their relevance. However, other witnesses testified that the short-term goals are unnecessary and that the IEP is merely a paperwork exercise, filled with meaningless criteria and overly-broad goals, rather than an effective teaching tool. One parent expressed frustration because at one point her child's IEP did not contain enough objectives. The school responded with an IEP that contained a total of 99 objectives!

IEPs do not have the proper goals. I had an IEP meeting yesterday. There were no academics on the IEP. (Linda Thompson, Anchorage, AK)

Witnesses discussed a variety of ways in which children with disabilities are partially excluded by a local education agency's inability or refusal to provide appropriate interventions, supports, and related services. In too many cases, appropriate services that have been mandated in a student's IEP and approved by the multidisciplinary team have not been provided appropriately or, in some cases, at all. Many witnesses testified about the cessation of approved related services because of an

independent decision made by an individual provider, a school district, or a district official:

Even though I was told that New York State education policies require that the same support services be available to children in private schools as they are to children in public schools, my request was denied. Finally, after much hard work I got the district to include consultant teacher services on my son's IEP. However, the city never implemented it, and we are now in the second year of having the city completely ignore its legal responsibilities.
(Karen Robard, New York, NY)

Witnesses identified a variety of other examples wherein services requested (and often approved) in IEPs were not provided:

- ◆ A school's refusal to teach sign language to non-verbal children as a communication technique;
- ◆ Delayed development of social skills in youth with disabilities because of their being transported great distances from home schools, rendering them unable to participate in extracurricular activities and limiting their social interaction with peers;
- ◆ Students who are receiving homebound instruction receiving only a few hours of direct instruction weekly; and
- ◆ The overall level of educator ignorance regarding special needs' populations and the IDEA, as well as a perceived lack of supports, staff, and funding for mandated, necessary, and required services and programming.

Parents indicated that the burden of obtaining services for their children and verifying the appropriate implementation of these services too often became exclusively their responsibility. This resulted in an adversarial or potentially adversarial dynamics among them, the school, and service providers. Although the obligation to identify children with disabilities and to provide them with appropriate services legally rests with

State and local education agencies, in practice, parents must assume the at times daunting responsibility to ensure that their children receive appropriate services.

Some witnesses made suggestions on how to improve IEPs:

- ◆ Definite timelines should be established for achieving goals and assessing the child's progress on a regular basis.
- ◆ Streamlined IEP options should be offered for students with speech and mild learning disabilities.
- ◆ An educationally relevant assessment should be a part of the IEP process and not a separate evaluation.
- ◆ The IEP goals must address acceptable behavior and related emotional issues in order to teach students to effectively manage their own behavior.
- ◆ The IEP should provide motivation to the child and encourage achievement, not merely state what the child will accomplish.
- ◆ A well-written IEP with meaningful goals can be an exceptional tool to teach and aid a child with a disability, but such an IEP must specifically state the goals and objectives to be accomplished by the child.
- ◆ A set of criteria to make the IEP process more effective for everyone should include: (1) self-evaluation by teachers, administrators, parents, and students; (2) careful monitoring of the process toward reaching the goals; (3) reevaluation and adjustment of teaching strategies when students are not reaching their goals; (4) completion of the initial evaluation in a timely manner; and (5) use of the IEP team more extensively to discover why a students are not reaching their goals.

The IEP and Teachers

We watched their education closely. This included many school visits. On one visit to school, the oldest child's seventh grade English teacher recommended institutionalization. It was all I could do to get my wife out of the classroom...From that point on, we avoided public school, except for

team meetings, or as I refer to them, "blood lettings." (Charles Packard, Boston, MA)

Aaron described the Rocky Mountain in Pennsylvania as being the best place he ever visited, where he used to go and sit and think...He wrote about the school as being the worst place he had ever visited, and he told me it was because the special ed teacher came into his class and didn't know how to teach him what he needed to know and tried to teach him what he already knew. (Karen McGinley, Boston, MA)

IEP goals are written based on what's available rather than what the child needs. (Pam Clingenpeel, Charlotte, NC)

"Appropriate" should never entail or be for the convenience of the school district. (Linda Bond, Charlotte, NC)

Many parents were concerned that their children were not receiving the services that they actually needed, but only those that were presently available. Witnesses stated their belief that needed services were not included in IEPs because teachers were hesitant to include services that were not currently provided or because too much paperwork was expected from them to prove that such supports, aids, or services were necessary for the child to obtain an appropriate education.

Teachers feel that they're unable to include a costly piece of technology in the IEPs for fear that their school districts will retaliate by potentially firing them if they request something that is not within the budget of the school district. (Cindy Berger, Anchorage, AK)

Additionally, a few teachers who testified expressed frustration in meeting the needs of their students with disabilities due to the large, diverse nature of today's classroom. Those teachers not "on the front lines" say they want to be better informed about students with disabilities and are concerned about the lack of compliance with the IEP process on the part of the "front-line teachers." Others testified that all of a

student's teachers should have a copy of the IEP: This information would heighten teachers' awareness of the student's goals and abilities and would help them incorporate those goals into their respective subjects. Another witness was concerned about teacher competencies and advocated the following:

Only personnel fully qualified within nationally recognized competencies or licensure standards will be permitted to deliver educational program within their field of expertise. (Tim Wallstrom, Anchorage, AK).

IEP Implementation and Enforcement

We have set up a system that I believe creates almost a tremendous bureaucracy in terms of making sure that we comply with hundreds and hundreds of rules, but there is no rule that says that we must have any kind of real successful outcomes for these kids. So we spend all our lives making sure we cross all our "T"s and dot all our "I"s, and people don't look to see whether the kids are doing better, whether they're being more successful. (Diego Gallegos, Albuquerque, NM)

We're so concerned about following what our immediate supervisor is telling us to do, and to create a cutoff, that will satisfy, maybe, the school board, to say that we are keeping the percentage of children down from receiving special education services. As a result, we're really kind of cutting our own throats in the end, because the children and families are really the ones who are suffering, and they're not allowed to continue to make those strides that they're making. (Mary Zeremba, Albuquerque, NM)

My son is desperate for an education, and there are hundreds and perhaps thousands of children like him in Maine who are desperate for an education but who have been told that they cannot learn, that they are lazy, manipulative and unmotivated, and to quote from one of his PETs last year, that he actually prefers to sit in the classroom like a dumb imbecile and not learn. I can assure you that this is far from the case. (Rosalba Votto, Boston, MA)

Various witnesses expressed dissatisfaction with public school systems because the schools were not complying with the goals and objectives in the IEP and teachers were

failing to follow through with even the simplest IEP requirements. However, participants at the hearings also made suggestions to remedy these problems:

- ◆ Harsher penalties and fines need to be stated in IDEA to notify school districts that noncompliance with IEPs will carry significant consequences.
- ◆ The language of Part B of IDEA should be strengthened regarding evaluation procedures and noncompliance issues, along with developing follow-up studies when the IEP goals for the child are established.
- ◆ With the three year reevaluation requirement, a monitoring system should be established to ensure compliance with current IEPs.
- ◆ Hold teachers and school personnel accountable for the implementation of IEPs. Establish severe penalties for teachers that fail to comply. (Debbie Stephens, Charlotte, NC)

Related Services

There are tools, right from computers down to switch operated toys down to low-tech, which allow kids to fully participate in their education...They can enable kids to get through all kinds of barriers...Failure to use these kinds of things is like denying somebody a pencil or a book, if they didn't have a disability. (Donna Dutton, Berkeley, CA)

I walked in one day and [said,] "Where's his self-feeder?...He's capable of feeding himself instead of having somebody spoon-feed him." (P.J. Carpenter, Anchorage, AK)

Parents and advocates for children with disabilities at each hearing site testified about the insufficiency of related services. Their primary concern was that when or if related services were determined to be necessary, many schools would only provide them if they were easily available. Thus, the criterion involved in the schools' decisions was *not* whether students needed related services as is required under the law, but whether these services were easy or inexpensive to provide.

In the absence of SEA or LEA policies on the provision of assistive technology, and the lack of Federal attention to assistive technology during SEA monitoring, it may be as difficult to assure the provision of a tape recorder or calculator as it is a closed circuit TV system. (Amy Goldman, Philadelphia, PA)

There is no adaptive equipment. [You would hear,] "Oh, oh. He is only one kid in the whole school." Well, doesn't that kid count? (Sam Reder, Anchorage, AK)

Being intelligent alone cannot get you over the hurdles that the learning disability presents. It requires other people to come in and help you with the technologies. (Mason Barney, Boston, MA)

Although parents felt confident enough to describe the services or assistive technology their children needed, they were often not successful in obtaining these because they were either unaware of their rights on this issue, believed school districts when told that the system could not afford the requested services, or felt too intimidated to confront school systems. Therefore, children did not receive appropriate services or assistive technology, received only minimal services, or received nothing at all, particularly if they were being schooled at home.

Witnesses stated that increased funding is needed to provide more services in a timely fashion and to provide more information and support to parents who are struggling to obtain appropriate services for their children.

We urge that the legislation be reauthorized with some strong mandates that schools address assistive technology needs and do it in a proactive way that provides training, that provides rights to individuals with disabilities and to parents so that, indeed, the program is individualized, not for the convenience of the system. (William West, Denver, CO)

Parents wanted better training for teachers and parents who need to be able to use assistive technology, clarification about issues of student evaluation for assistive technology, and more compatible equipment in the system to enable smoother transitions from one level to the next (e.g. being able to use the same computer system in grade school and high school so time is not wasted in adapting to new technology).

Transition of this technology from education to work, from one educational setting to another, has to be a primary emphasis of the use of adaptive technology in the education system. One form of transfer of technology that concerns me greatly is that ability not only to move from system to system, but from the 9-to-5 part of their lives to the 5-to-9 part of their lives, being able to bring that technology out of the classroom into the home, to use it in manners appropriate for personal management of their home lives, as well as to do the homework associated with education. (Brian Charleson, Boston, MA)

Because...items cannot go with him to the next school that were purchased by the previous school just for him,...we're back at the square one going, "Okay, we need this...type of equipment for him to use so he is capable of doing what he needs to do in the classroom." (P.J. Carpenter, Anchorage, AK)

We also need to teach those teachers to use technology to advance educational opportunities...to take a computer, type in the textbook, be able to translate it and print it out in braille at will. Worksheets should not be something that are read aloud or hand transcribed in these modern times...The whole concept of teaching materials...I remember when I was in school and took things like Art History, required subjects, one of the joys of that experience was trying to sit through umpty-ump slide shows with somebody trying to describe to me the difference between pointillism and cubism without one single raised-line image to learn from, trying to do it entirely from description. I'm very concerned that in the educational system, as we continue on into technology and see videos taking an ever-increasing importance in the classroom, that those be made accessible. (Brian Charleson, Boston, MA)

Last year was the first year that Chris had any consistent access to a computer, although it has been in her IEP since kindergarten and she is now in the sixth grade. (Tracy Hunter, Charlotte, NC)

With respect to deaf or hearing impaired children, parents expressed a desire to have an increased number of certified sign language interpreters. They were concerned about the quality of interpreters working in the schools. Because communication is essential to effective learning, some witnesses suggested setting national standards for interpreters. Additionally, parents stated they would like to see guidelines for language therapists incorporated into IDEA.

A number of parents and advocates made specific suggestions, including listing school health services delivered by a professional school nurse as a related service.

The law doesn't clearly state who is responsible for providing these services [related services for students with medically-related needs]...Failure to clarify this part of the law keeps individuals who choose to participate in the least restrictive environment segregated from their peers without disabilities, and loopholes for professionals who use the "medically fragile" label to keep these children out of the community and out of community schools.
(Beverlyn Lee, Berkeley, CA)

There was also some consensus that services should be provided to meet the needs of students with neurobiological disorders. Certified school nurses could administer and monitor medications taken by students with neurobiological disorders, thereby creating access to the public school system. In addition, one parent requested respite care as a related service for parents like herself who are caring for a child with severe anger and attachment problems.

Other concerns included transportation problems, particularly in remote areas. Rural areas throughout the country seem to be at higher risk for being unable to provide necessary services, due at least in part to the physical geography of these areas complicated by the relatively low numbers of people with disabilities in these areas. This situation creates transportation hardships for parents when transportation is either not provided by LEAs or when students must spend extended blocks of time on busses or other district vehicles. Regardless of the law's intent, witness accounts indicate that there is no uniformity throughout the nation regarding which school districts will provide transportation, reimburse parents for providing the service, or simply refuse to offer the service. This places special education and related services outside of the physical reach of many children in need.

Other parents complained that their children have to commute long distances every day, are being picked up during class time so teachers can use the extra time to plan the day (depriving children of 40-50 minutes of the regular school day), or are being denied transportation altogether.

The Overall Benefits of Special Education

Witnesses testified that when a student does not receive appropriate and necessary services and skill training, the student will not progress or benefit from special education. While there are clearly situations in which students have benefited considerably from their involvement in special education, in far too many instances the

absence of appropriate services has resulted in unsatisfactory levels of student achievement. One parent testified that upon initial evaluation, her child was reading at a first-grade level. After appropriate services were provided, her child progressed to a fifth-grade reading level within one-and-a-half years. However, most of the testimony indicated that students were not fully benefiting from special education:

Even as a 15-year-old...I knew that special ed was the plague....I didn't want to be put in a five-by-five room with a single teacher and a piano. It was like being put in jail....My consciousness vis-à-vis disability was particularly heightened at an early age, and I knew that the only way for my peers, and teachers, for that matter, to learn to deal with disability was to face disability. Being herded into that room wasn't doing me any more good than it was doing them. [I] have a lot of concerns about people with physical disabilities being herded into special ed even though they don't need to be in a special ed program. (Drew Sommers, Milwaukee, WI)

Teachers are supposed to...comply with the modifications. I've had teachers make my grades higher, because if they flunked me, we'd go back asking what kind of modifications [could be made]. For instance, just recently...I did not turn one paper in, in math, but I had turned in two tests, which were both "F"s. I still came out with a C. So, see...this is their answer to modifications, just make the grade higher. I actually want to get something out of education. I want to learn something. I don't want people just putting my grades there for me. (Michael Klucher, Albuquerque, NM)

...Receiving straight A's throughout school, I went on to college unaware that I was so unprepared, totally unprepared. Fortunately, I had the smarts and the continued support of insightful, intelligent parents, helping me through the traumatic beginning. I went to graduate school, but my high school education was far from "special." It was deficient. (Suzanne Bacal, Philadelphia, PA)

Students come out of [special education schools] with nothing that looks like a diploma. They get a certificate of attendance, a certificate of completion...None of those...is a diploma. So a kid can go from kindergarten to the end of his or her education career with nothing that looks like what every other student is to get. So they don't come [out of school] equipped....Our kids with disabilities are just like kids with able bodies [and] are supposed to get real life education while they are in school that is

augmented by the community and their parents. (Greg Dougan, Philadelphia, PA)

My son is an 18-year-old person with a third-grade education. He wants to go to college. He wants to be a marine biologist. But he may never get out of high school because he hasn't been given the right skills and the right tools. [He] has been made to feel...that he is moron, that he will never catch up. (Rosalba Votto, Boston, MA)

As a Director of the Independent Living Center, we primarily serve adults with disabilities. Well, we've seen the failings of the special ed system for the past two decades. Many of our consumers who have come out of special ed don't know how to read, don't know how to write, have never been taught basic fundamental skills that are necessary in our growing work- and technology-based society. (Paul Spooner, Boston, MA)

We see the aftermath of the educational process on adults with disabilities...Statistically, many adults with disabilities do not have sufficient education to enter the competitive market, and as you know, our society is changing rapidly. (Rafaelita Bachicha, Albuquerque, NM)

When he graduated this year, he [couldn't] read or write. He was never taught the technology that could have helped him function as an adult. He entered school with an IQ of 109, graduated with an IQ of 86. I don't really believe his IQ dropped, but I believe the system failed him. (Cindy Sirois, Boston, MA)

At age 12, she left public school [with] a second-grade education. This is a horrendous, horrible use —or nonuse— of an education system. (Robin Ann Tracy, Boston, MA)

Clearly, these customers of special education were not satisfied with the results of their experiences in the system. While it is undeniable that special education has had tremendous positive impact on the quality of life experienced by those who have received appropriate education, the testimony of these witnesses indicates that many families and students are not receiving a free and appropriate education consistent with their needs as the law intends.

Alternative Placement

We were told at her IEP meeting by the special ed coordinator that we were like pioneers in the process of allowing the school to educate my daughter. I cringed and thought to myself, to me "pioneer" is synonymous with "guinea pig." (Kathleen Fitzgerald, Boston, MA)

Some parents, frustrated with the schools' reluctance or refusal to provide services to meet their children's needs, have resorted to private placement or home schooling, sometimes at their own expense. Parents and advocates testified that in far too many schools, special education students were unwelcome, were frustrated as a result of inappropriate services, or were deteriorating due to a lack of appropriate services. In spite of 20 years of experience, it is still the case that in many locations, virtually no services are provided in public school buildings for students with moderate to severe disabilities. The troubling effect of this *de facto* non-compliance with the law has been the assumption on the part of a whole generation of parents in these locations that their children *cannot possibly be accommodated in a regular school environment*. And yet, in every hearing there were parents who provided powerful examples of how individual school districts had designed and implemented high-quality services and supports for students with even the most severe disabilities in regular public school buildings. In some situations these districts literally bordered on districts that provided virtually no services to students with moderate to severe disabilities in regular schools.

It is, of course, understandable that when parents are offered no (or very limited) services for their children with disabilities in regular school environments, they will

accept placements outside of the regular school system in order to access help for their children. As we will see in the chapter on "Least Restrictive Environment," tremendous barriers still exist in accessing this help in typical public school buildings. However, in many parts of the country, the most important issue is not a lack of alternative placements. Rather, it is the substantial lack of ordinary placement options.

Recommendations: Appropriate Education

In order to ensure that IDEA's provisions regarding appropriate education are improved and strengthened, the Federal government should implement the following recommendations:

1. Require State and local education agencies to offer information and training to parents regarding their participation in the special education process, particularly as this relates to active involvement in decisions regarding their child's education.
2. Over the past 20 years, the Individualized Education Program (IEP) has served many purposes. There is currently great variability in the processes used and results derived from the development of IEPs. The Department of Education should succinctly catalogue the overall purposes of IEPs and reaffirm the most basic purpose of the IEP, which is to ensure that students receiving special education are provided with a carefully tailored package of supports and services designed to maximize their educational achievements within the least restrictive environment.
3. Within the context of renewed emphasis on the basic purposes of IEPs, the Department of Education should monitor progress in improving the quality of IEPs. Such monitoring should go beyond the current infrequent and highly formal monitoring program and include new approaches such as stratified sampling of parent and student satisfaction and the solicitation of input from teachers and other professionals on how IEPs might be improved.
4. With the adoption of the recommendations above, the Department of Education should allow greater flexibility —based on informed decisions made by parents and students— on the degree of specificity required in those parts of the IEP that deal with day-to-day instruction and the delivery of related services. For example, some parents feel that there is no need for short-term objectives in their children's IEPs. Other

parents would like to see a "shortened" IEP for students with relatively minor disabilities. Greater flexibility in this area would likely lead to greater levels of customer satisfaction and reduced paperwork.

5. The Department of Education should provide incentives and support for State education agencies to improve their monitoring of the performance of local education agencies, particularly in situations where State education agencies are attempting to provide sanctions for substantive noncompliance with the provisions of IDEA on the part of a local education agency.

6. The Department of Education should require State grantees under the Technology Related Assistance for Individuals with Disabilities Act to engage in more extensive outreach to school districts regarding the availability of assistive technology devices and services.

7. More funding should be available to provide necessary assistive technologies and support services that enable students with disabilities to attend school and to increase their independence.

LEAST RESTRICTIVE ENVIRONMENT⁶

Statement of Law

The least restrictive environment (LRE) principle in IDEA creates a presumption in favor of educating students with disabilities in the same programs as students without disabilities. Thus, to the maximum extent appropriate, a student with a disability is to be educated with students who do not have disabilities. IDEA requires that the student's removal from the regular educational environment may occur only when the nature or severity of the student's disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (20 U.S.C. Secs. 1412 (5)(B) and 1414 (a)(1)(C)(iv)). In addition, State and local education agencies must maintain a continuum of placements (34 C.F.R. Part 300, Secs. 300.17 and 300.551). The continuum includes instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions.

Under IDEA, a student's placement should be determined annually, be based on the student's IEP, be as close to the student's home as possible, take into account any potential harmful effect on the student or the quality of services the student needs (34

⁶ This area is of such vital importance to the improved implementation of IDEA that the National Council on Disability has recently issued an entire report on this subject entitled, *Inclusionary education for students with disabilities: Keeping the promise*. The report covers areas such as examples of successful inclusion across the age span; specific strategies for making inclusion work; continuing barriers to inclusionary education; financial barriers and opportunities; professional and consumer training; and the effects of inclusion on the total school. While the report was based on a different set of hearings, the results were remarkably consistent with those in the current report.

C.F.R. Sec. 300.552), and the likelihood that the student will be so disruptive in a regular classroom that the education of other students will be significantly impaired (note to 34 C.F.R. Sec. 300.552).

Benefits of Integration

At every hearing, witnesses offered strong support for IDEA's fundamental assumption that the first placement option to be considered for students with disabilities should be the regular classroom the student would attend if he or she were not disabled. Such placement was variously referred to as "integration" or as "inclusion" by witnesses in their descriptions regarding the benefits of such placements.

Toni Robinson is a parent and educator at the Parent Training and Information Center in North Carolina. Her eleven-year-old son, Ted, has Down syndrome and is in his second year at a regular elementary school:

Over the last year, I have learned that IDEA works, and the least restrictive language in IDEA, in my opinion, is just fine as it is. I can tell you that supported inclusion, which entails support for students and parents, for my kid, I can tell you that it works, period. I have a kid. My kid has a life. And I can say to you honestly I really feel like now I have a child instead of a walking disability: walking Down syndrome. And a year later, I have those feelings corroborated by folks at the school, who say, "I wish we could have videotaped this child every day since he walked in the building, because no one would believe the progress." (Toni Robinson, Charlotte, NC)

Many other witnesses described the benefits of integration:

Had I been placed in that special classroom, would they have taught me to expect the same things for myself that children without disabilities take for granted, or to accept a standard that was less? Would I have learned to climb stairs, or would they not have taught me because, like the public

school nurse, they would be afraid I might fall? Would having attended a special classroom [have] prepared me for college, or would it have ended my chance for a bachelor's degree before it was begun? (Bernadette Griffin, Philadelphia, PA)

Experiences with Keith's new teacher and his classmates leads me to understand inclusion, like education for any typically developing child, is a process in which placement is crucial. Disability is real. It's educational implications cannot be ignored. However, we already have demonstrated adequately that poor quality of life outcomes can be predicted by mindlessly segregating individuals with disabilities. (Walter Theis, New York, NY)

The main "benefit" Darcy drew from her experience in segregated education was the internalized idea that she could not do what other children could do and was somehow not equal to them. (Leslie Reed, Denver, CO)

In every step of her education, there have been other parents who came to me privately and thanked me for allowing their children a first-hand human experience of the children who for so many years were relegated to special classrooms, other campuses, for separate —but not equal— education. (Lindsay Merryman, Berkeley, CA)

For many witnesses, placement in the least restrictive environment meant placement in a regular classroom in the neighborhood school they would attend if they were not disabled:

Integration into home schools results in education of the community to the sensitivities of children with disabilities. (Mark March, Des Moines, IA)

While having Alex attend his neighborhood schools has not been a popular idea, we have settled for nothing less than being given the opportunity to go to the same school he would attend if he did not have a disability. (Greg Omori, Des Moines, IA)

Parents whose children were placed in local neighborhood schools were pleased and convinced of the many benefits of such placements. Not only does the community

learn to accept the particular student, but the student also gains socially and emotionally by having companions in the neighborhood that attend the same school. One little girl testified that she was very thankful that she was able to go to her neighborhood school. She expressed sympathy for another girl she knew who attended a segregated school because she did not have this opportunity and has no friends to play with in the neighborhood.

A majority of witnesses who testified on the subject of least restrictive environment indicated strong support for integrated placements. This support was based on a variety of factors. Many parents of students with disabilities stated that their children made greater gains academically and socially in integrated settings than they had in segregated settings. Parents emphasized the friendships their children had made with nondisabled students that would not have occurred in segregated placements. Parents reported that their children were happier and were eager to be doing what their peers were doing.

Catherine Jortner, President of the Connecticut Coalition for Inclusive Education for Students with Disabilities, spoke on behalf of the parent of a student with autism. The parent had spent five years in due process proceedings, trying to have her son included in a regular classroom setting. She was successful and reported that the five years of struggle had been worth it, as it offered irreplaceable social benefits to her son, Jay.

For the first time, at age 16, Jay went out with friends. He went to a football game with some classmates. It's funny, we were always told that regular education kids just don't want anything to do with special education kids. The kids at the high school have been wonderful. Adults could learn a lot from them. He has friends. Now we have hope for his future.
(Catherine Jortner, Boston, MA)

Furthermore, students with disabilities and their parents indicated that academic standards are higher in integrated settings and that students are motivated to achieve at higher levels, whatever their initial level of ability and functioning. Witnesses also reported that integrated placements often led to a greater ability to achieve independence and employment as adults.

Kathleen Fitzgerald is both a teacher and a parent. Her daughter, Kara, who has both mental retardation and autism, was successfully included in a regular classroom:

We saw more progress in that one year of inclusion than we saw in six or seven years of very intensive one-on-one special education. So I feel very strongly that IDEA certainly helped me, and the new...recognition of autism helped me to be able to get my district to look at including my child with very obvious behavioral and autistic tendencies in a regular classroom. [It] was unbelievably successful! (Kathleen Fitzgerald, Anchorage, AK)

Both parents and students stated that they preferred a real-life environment with a diverse population because integration helps students without disabilities to become more compassionate and understanding. Linda Frederick is a parent who, in 1971, worked in an institution for people with mental retardation, including people with Down syndrome. She now has a son with Down syndrome and is very pleased that he is being

educated in an integrated environment, remembering the institution where she once worked. She feels fortunate to have great teachers and services that have been especially beneficial to her son's socialization. She says that her son will learn a lot from the kids, a little from the specialists, and a little from the general education teacher.

My son, our family, his friends, and his school are all the beneficiaries of his inclusion at Columbine. I no longer fear for his future. His inclusion in school will ensure that he's included as an adult. There's no better feeling than to know that. Most important of all, he will learn about finding his place in the world, and his friends will learn about finding their place in the world. (Linda Frederick, Denver, CO)

The costs associated with integration can be modest, with possible savings because of fewer due process hearings, fewer mediations, fewer referrals to special education, fewer non-public school placements, and lower transportation costs.

Oakland's current inclusion program at the elementary level serves 27 students at eight schools. Over 60% of the Severely Handicapped (SH) students living in those eight attendance areas attend regular education classes in their neighborhood school with the support of supplemental aids and services...This year OUSD [Oakland Unified School District] will spend about \$800 per inclusion student less than the cost of educating them in SDCs [Special Day Classes]. This is due largely to transportation savings (\$2,310/student) offsetting additional costs due to staffing (\$1,370/student), planning, and training.

As more students are included across the district and at all grade levels, there will be additional costs for equipment (averaging up to \$250 per included student), ability awareness training (about \$20,000 per year district-wide), and reduced savings on transportation at the secondary level. However, any additional costs should be completely offset by projected savings from:

- ◆ *reduced escalation to more intensive services (e.g. about \$32,000 per student per year not referred to non-public school);*
- ◆ *reduced legal fees associated with mediations and fair hearings (typically \$2,000 — \$10,000 per case);*

- ◆ *reduced need for expansion of facilities (\$55,000 per classroom);*
- ◆ *reduced facilities usage (\$960 per class per year); and*
- ◆ *the effects of economies of scale (e.g. potential for reducing staffing at \$1,370 per student per year).*

Inclusion represents a more efficient and effective utilization of educational resources. Furthermore, the substantial benefits attributed to inclusive education can be delivered for no additional expenditure of resources. (Mark Polit, Berkeley, CA)

Individuals from advocacy organizations also testified in favor of integrated settings. These advocates represented parents (including parents from diverse backgrounds), students with severe disabilities, and people with mental retardation. The few special education administrators who testified generally supported the concept of integration and emphasized the need for administrative support for integration within school districts.

Beyond the numerous statements of support for integration, many individuals also commented on the negative effects of segregated settings. Ellen Laurence is the parent of a daughter who was placed in a self-contained special education classroom after having been in an integrated setting. In the self-contained program, she was physically abused by staff. She testified that when she reported this to the Colorado Department of Education, she was told that abuse was not their problem, but that it was a personnel problem.

Students reported that they had been ridiculed and stigmatized for going to "the special education room" and that they were treated like second-class citizens. One student reported feeling *psychologically malnourished* when placed in a group made up only of other young adults with disabilities (Bill Rush, Des Moines, IA).

A number of witnesses stated that a separate special education system could never be equal to the regular system. Some stated that children with mental retardation in segregated settings frequently miss out on academics and the positive behavior modeling of nondisabled peers. Others stated that segregation may encourage nondisabled students to maintain harmful attitudes, because segregation demonstrates that it is acceptable to treat some students under different rules and because nondisabled students do not have the opportunity to know students with disabilities as peers and as individuals. Several individuals stated that segregation itself creates a further disability, perhaps worse than the original disabling condition. Thus, the supported integration of students with disabilities was described as not only producing better results for all students, but as a positive instrumental method of reducing the historical prejudice that has been directed toward people with disabilities in our culture.

Characteristics of Successful Integration

Once the child is there...[inclusion] sells itself. (Jan Miller, Berkeley, CA)

The teacher that honestly believes a child is an asset to the class and is a privilege to teach communicates much to that child, and sets an example for the rest of the class to value all people. (Gayle Underdown, Charlotte, NC)

Her team is creative, flexible and determined to make inclusion work. (Janet Schmitz, Berkeley, CA)

Primarily [it is] the kids who are really into, in fact, including Adam. They are the primary sources of strategies and ways to include him in all their activities starting from PE through their curriculum. (Joanna Cooper, Berkeley, CA)

A large number of witnesses who commented about the characteristics of successful inclusion credited staff members who work directly with students with disabilities. Positive attitudes were frequently mentioned as critical to the success of integration. Staff who want to make integration work, or even a single teacher who promotes positive attitudes about people with disabilities, can make all the difference. The quality and training of regular teachers, special education teachers and support teachers and staff in successful integrated placements is an important factor. So is collaboration among teachers, between teachers and parents, and between schools and agencies. Some individuals stated that support from the administration and school district is necessary, as is provision of adequate support services to the child and classroom teacher. Support services can include early intervention, paraprofessionals or aides, interpreters, buses for field trips, and education for nondisabled peers. Obviously, appropriate IEP goals and objectives are necessary.

The role of other students is also important. Social interactions between students with and without disabilities can be encouraged. Peers naturally provide motivation, can suggest curriculum modifications, and become friends of students with disabilities.

Diana Daggett is a parent and board member of the Autism Society of America. Her 15-year-old daughter, Allison, is succeeding in a regular school because she has proper support and her school is complying with IDEA:

Allison is living proof that with the proper supports and compliance by schools, children with special needs can succeed. What's important is the reputable fact that all children benefit from full participation of every student. There are important lessons to be learned early in life about the rights of all people. (Diana Daggett, Albuquerque, NM)

Barriers to Integration

While a large number of witnesses described the benefits of integrated education, many others described the many barriers that continue to impede (or serve to prohibit) the implementation of IDEA's requirements.

Attitudes of Professionals in Education

I tell you in my experience, I've heard such rhetoric as, "I'm getting tired of spending money on kids who aren't ever going to grow up and be anything." Holy cow, and that's coming from administration! (Mark Peterson, Des Moines, IA)

Attempts by parents for mainstreaming or inclusion are met with disdain and indifference. (Pam Clingenpeel, Charlotte, NC)

We've been told, "You're going to dump these children in our class and we're going to be responsible to teach them. If we don't, it will be our jobs." (Greg Omori, Des Moines, IA)

One parent was told from an administrator, "[Your son] can either go to his neighborhood school, where he will be teased and humiliated, or he can continue to go to the segregated school, where he will have the opportunity to be class president and captain of the basketball team." (E.J. Jorgensen, Des Moines, IA)

Of the approximately 50 people who discussed professionals' attitudes, several testified that many teachers are unhappy with inclusion and are not always receptive to having a child with disabilities in their classroom. One parent said that her daughter who has autism was subjected to regular classroom teachers who ignored her, blamed her for requiring special help, and pressured her parents to segregate her by taking her out of the integrated system. Another parent stated that in her city, the teachers' union wants a moratorium on inclusion and teacher "veto power" over the acceptance of students with disabilities into their classrooms, a situation that would be intolerable in the treatment of any other minority group. A father from Anchorage stated that he was afraid that his child would be excluded if his child's disability was identified due to the lack of personnel support for inclusion. A few people testified that, although some teachers initially support integration, they want to revert back to segregated programs as soon as any problems arise.

People compared the situation of children with disabilities with that of the discrimination that occurred against African Americans a few decades ago and stated the strong hope that it will not take decades for people to come to the understanding that children with disabilities belong in a classroom just as much as nondisabled children.

Inclusion must be a right for all and not a privilege for a few. (Kathie Snow, Denver, CO)

The inclusion of all of our kids hangs in the balance until districts and LEAs and SEAs stop seeing inclusion as a favor to be given or denied and see it as a right for all of our kids. (Cheryl Ogle, Des Moines, IA)

Why should parents have to struggle so hard to access inclusion when the original intent of IDEA was to make the regular classroom the first option of choice? (E.J. Jorgensen, Des Moines, IA)

Least restrictive placement is [considered] an earned privilege, not a right. Children must prove that they can attend, keep up with, and function as non-disabled students in the regular classroom or they do not have the right to attend. (Dawn Gloss, Des Moines, IA)

I've been watching inclusion evolve over the last six or seven years. Inclusion works wonderfully for students [who] have parents that have the time and energy to support their child. (Jane Thiboutot, Anchorage, AK)

Approximately two dozen witnesses testified on the negative attitudes of professionals as a barrier to inclusion. A large number of parents complained of having to fight —sometimes for years— for their child's right to integrated education. Several complained of having to hire attorneys to fight for integrated placements that were supposed to be their children's right. Furthermore, contrary to the provisions of the law, witnesses stated that the burden is often placed on students and families to "prove" they are "ready" for inclusion, and only then do they "earn" their way out of a segregated setting.

Parents expressed frustration that their children with disabilities had been sent to schools away from their brothers, sisters, and friends, especially when the appropriate services could be made available in their neighborhood school. General resistance to integration is a factor many believe to be the main obstacle behind administrative reluctance to integrate students with disabilities into regular schools.

While positive attitudes are a key element in reducing barriers to inclusive education, occasionally a witness noted that attitudes can be changed:

I used to think that teachers had to have the right attitude and the right training before kids could be included in their classroom. And what I found from experience is that sometimes when you include a child with diverse needs into their classrooms, their attitude changes, and they see the need for training and they will get it then. (Charmaine Thaner, Denver, CO)

Personnel Preparation

I don't get it. Why all the opposition? Aren't these people in a position they are in to help guide education to be the richest it can be? These people who oversee the education are, by example, teaching mediocrity, intolerance, and purposeful ignorance. (Elsie Mahler Scharff, Philadelphia, PA)

The problems with obtaining integrated placements, coupled with the poor and unsupportive attitudes of professionals, stem at least partially from a lack of training for educators and administrators on the purposes of integration and on techniques to implement this requirement of IDEA successfully.

I think it's important to teach teachers disability awareness. Non-disabled teachers probably don't have an idea of the personal psychological effects of disabilities. (Julie Redenbaugh, Albuquerque, NM)

[At the college I attend,] they teach that including students with disabilities is against the LRE requirement and that segregated classes and schools are the best environments for students with moderate or severe disabilities. (Patty Gilg, Des Moines, IA)

Over 20 people identified the need for improved personnel preparation in (1) working with students with disabilities and their families, (2) learning about disabilities in general to promote understanding, (3) understanding IDEA and the requirements of LRE, (4) focusing on the students' abilities as well as understanding their disabilities,

and (5) training administrators. Administrators need to become more familiar with what is involved in including a child in the regular classroom. It is only then that they will have a foundation to be able to support teachers in the inclusion of students with disabilities in their schools.

Jane Burke is a parent whose seven-year-old son experienced successful integration in kindergarten because the teacher was accepting, tried hard to address him in her lessons and activities, and modified his assignments to give him work at his level. She testified, however, that in a different grade, the teacher was inflexible and unwilling to adopt or modify the curriculum or produce incentives for good behavior:

In my experience, the real barrier to children with disabilities being placed in a regular classrooms is unaccepting attitudes of school personnel. It is difficult for people to change. It's been easy for them to hand children over to special education and not have to deal with anyone with different needs. It is our job to show teachers and school administrators that we believe all children can learn and deserve to learn together. (Jane Burke, Philadelphia, PA)

Funding and Costs⁷

It is clear that current funding patterns create incentives for segregated special education and disincentives for integrated education.

⁷ For a further discussion of barriers to the financing of inclusive education, see: Education Development Center (1994). *A system apart: A study of the implementation of the least restrictive environment provisions of IDEA in Massachusetts and Illinois*. Newton, MA: Author; and National Council on Disability (1994). *Inclusionary education for students with disabilities: Keeping the promise*. Washington, DC: Author.

If we look at the bottom line —money— Iowa's system is set up, "The more you segregate, the more money we will give you. We will give you more money if you separate the children." (Greg Omori, Des Moines, IA)

These laws are wonderful, and yes, they work, but they don't work without money. (Kathleen Fitzgerald, Anchorage, AK)

More than 40 persons testified about the issue of financial disincentives to integrated education. In many States, school districts receive more State funds by labeling and segregating students with disabilities than they do for integrating these students into regular school environments. This type of State funding practice causes local education agencies to segregate students with disabilities because districts cannot afford the supports and services necessary for quality inclusionary services with no (or reduced) State funds. One parent commented that in order to have his son integrated, he had to discover a way that the school district could still receive its money while integrating his son. Another described her experience as follows:

Our first introduction to our district came with our son being labeled as S.H. For those who don't know, "severely handicapped." He had never received such a label before. We were given a cursory explanation that in California, this label was used primarily as a funding mechanism, not as a placement tool. But we quickly learned that our son had a bounty on his head. (Cecily Purcell, Berkeley, CA)

To provide an incentive for schools to follow IDEA, one witness recommended pooling the resources of different categorical programs. The effect would be to eliminate the negative reaction that often exists when regular education funds are used for special education.

But [successful inclusion] cannot happen unless the board provides the resources, the training for the staff, and there is an attitude change in terms of staff and personnel as to the possibilities of children being allowed to function in a regular classroom situation. (Sonia Ortiz-Gulardo, New York, NY)

In addition, the current lack of resources in general and special education alike can prevent the effective and appropriate inclusion of students, because the appropriate services are not always available. For example, one mother said that her daughter who has a learning disability was mainstreamed, but did not have a consultant teacher because there was not enough money in the budget to pay for one. While a lack of resources is not an acceptable excuse under the equal protection provisions of the Constitution upon which IDEA is based⁸, school districts continue to use this excuse to deny services to students with disabilities.

Many witnesses stated that resources need to be allocated for personnel preparation, particularly for the education of professionals in the integration of students with disabilities and for collaboration between regular and special education teachers in order to monitor and improve integration efforts.

Partial Integration

Some witnesses commented specifically on the unsatisfactory implementation of the LRE through only partial or poorly supported integration:

⁸ See *Mills v. District of Columbia Board of Education.*, 348 F.Supp. 866 (D.D.C., 1972).

I've been in some classrooms where there are children who stay in the back of the room in the corner and are ignored for a couple of hours at a time... that's not inclusion. (Jane Thiboutot, Anchorage, AK)

Even though students might be physically integrated into a regular school program, accommodations may not be made in order for these students to access effective instruction and social supports. For example, one witness expressed concern regarding the lack of academic integration. Too often, children are integrated only in classes such as art, gym and music. Another witness was dismayed that her child was allowed social interaction only during lunchtime.

While placement in a regular neighborhood school does not dictate that a student with disabilities spend every minute of the day in regular classes, it is also the case that the ability of students with disabilities to participate in regular —and challenging— classes within the regular school should not be prejudged.

Being Treated as a "Burden" to Regular Education

Congress included an exception to the IDEA provisions regarding least restrictive environment to address the rare situation where a student's behavior in a particular placement might be considered dangerous to the student or to other students. Unfortunately, this exception has been sometimes used to exclude students whose behavior would not be construed as dangerous (see the "Zero Reject" chapter). While it may be necessary to continue this exception in the law (although such behavior is

covered under other laws), its interpretation should at least be restricted to those situations for which it was intended:

We feel that the IDEA adequately addresses the issue of children having dangerous behaviors by the process that school districts can get an injunction for a child who is dangerous. (Teresa Holt, Anchorage, AK)

Parents reported that in some situations, they had been made to feel that the presence of their child in a regular school environment would hinder the progress of other students or that the "burden" of providing services to their child would take resources away from other (presumably, more worthy) students.

Continuum of Services

When IDEA's predecessor, the Education for All Handicapped Children Act, was written 20 years ago, Congress mandated State and local education agencies to provide a continuum of services in educating students with disabilities. This continuum included a graduated series of increasingly restrictive and segregated placements for students with disabilities, ranging from placement in regular education classrooms to institutions. This requirement continues in effect to this day.

[It is not possible to have] a one-size-fits-all educational philosophy. (Stella Sanfratello, Denver, CO)

[Inclusion] is not the answer for every child or for every parent. We have children that are benefitting from inclusion, but we have many children who are vegetating in the backs of classrooms. (Julia McCarthy, Boston, MA)

I have some serious concerns about the current movement to adopt inclusionary practices as a single, universal concept to meet the needs of deaf and hard of hearing. (Timothy Jaech, Milwaukee, WI)

Some witnesses at the hearings testified in favor of maintaining the continuum of services. Their comments were often based on the type of disability that their child had. For example, individuals who were deaf and parents of students who were deaf constituted the majority of the individuals who wanted to maintain the continuum. Some parents of students with multiple disabilities also supported the maintenance of the continuum. Individual parents and persons representing other disability groups —such as blindness or visual impairment, mental retardation, other developmental disabilities, attention deficit disorder or autism, and dyslexia (in decreasing order of frequency)—also testified on behalf of the continuum.

Several witnesses offered explanations as to why they wanted to maintain the continuum. Some stated that their child's needs simply had not been met in the regular classroom, primarily because the school failed to appropriately educate them by not providing necessary services. This comment was especially frequent for individuals who were either blind (or visually impaired) or had multiple disabilities. Others stated a general need for flexibility and parental choice in the matter. One woman commented that her daughter became frustrated in the regular classroom trying to keep up with the other students, but once she was placed in a segregated school, she started learning again. A few parents of children with multiple disabilities commented that they preferred separate placements because of the medical supervision provided for their child. Individuals who were blind or visually impaired expressed their concern that

braille education simply had not been made available in integrated settings. One individual stated that he had been integrated and had benefitted socially, but that he lacked a lot of necessary skills.

Witnesses concerned with students who are deaf cited several reasons for maintaining the continuum: the lack of language education in many integrated settings, isolation from peers because of communication barriers, and underdeveloped self-esteem due to a lack of role models. Additionally, they valued the availability of direct communication with the teacher and peers without having to rely on interpreters to communicate.

The individuals who testified in favor of the continuum did not express a desire to eliminate inclusion. As noted above, many indicated that they had chosen other placements because appropriate supports and services had not been made available to them within regular education settings. In the case of deaf students, Cliff Moers explained that the development of communication skills was paramount:

When there is communication, then they will learn. There is no way to learn except through communication. Compared with other children with disabilities, our group is unique, and our needs are related to communication and communication barriers. That's our biggest problem. (Cliff Moers, Denver, CO)

Thus, it is the case that 20 years after the passage of the law, there are students who are not being served well —or served at all— by the public schools. However, given the existence of highly successful models of inclusive education for students with

all types and severity levels of disabilities all across the nation, the time is long overdue that, with the possible exception of deaf students, the focus of the placement question evolve from the initial assumption that the nature or severity of a disability determines a certain placement on the continuum to a focus on the availability of appropriate supports and services within a given local education agency.

Recommendations: Least Restrictive Environment

To date, most governmental parties involved in implementing the requirement that students receiving special education be educated in the least restrictive environment have consistently failed to live up to their responsibilities regarding this requirement. Twenty years after the passage of Federal special education legislation requiring placement in the least restrictive environment, many local education agencies continue to routinely place students with special needs in segregated categorical programs with virtually no consideration of less restrictive placements. State agencies continue to reward this noncompliance in many parts of the country by providing financial incentives for segregated placements. The Federal government has failed to enforce the law in any substantive manner, thus aggravating the situation.

In spite of this, thousands of students with all types of disabilities, including those with the most severe levels of disability, are being well supported —and are thriving— in full-time regular class placements across the country every day. Clearly, we have gone beyond the point where arguments can be effectively made that some students simply

cannot be served in integrated placements because of the nature or severity of their disabilities. And yet, the entire national architecture of special education continues to be based on a structure known as a continuum, which was originally developed on the assumption that the nature and severity of a disability should determine the degree of integration or segregation a student experiences in education.

Continuing noncompliance with the least restrictive environment provisions of IDEA is particularly troubling in light of the provisions of the Americans with Disabilities Act of 1990 (ADA). One of the core goals of the ADA is a significant increase in the participation of all Americans with disabilities in the lives of their local communities. In stark contrast to this, most public schools continue to segregate large numbers of students with disabilities from participation in the lives of their neighborhood schools, and sometimes even their communities. This continued segregation may be construed as a *de facto* violation of the civil rights of students with disabilities under the ADA. Clearly, special education law should not promote service structures that justify and promote the segregation of students on the basis of the existence, nature, or severity of their disabilities.

Accordingly, a major goal in improving the implementation of IDEA should be replacing the requirement that State and local education agencies must provide a continuum of services with a requirement that State and local education agencies must provide for an "array of support services designed to maximize the student's

participation in regular education environments and activities." A continuum, by definition, is constructed with a series of steps leading away from regular class placement. An array, on the other hand, can be conceptualized as having a wide variety of individually accessible, discrete support services that can be accessed freely from a regular educational environment. Under a continuum model, students are incrementally removed from typical educational environments and they and their parents must accept all of the features provided within their "step" on the continuum. With an array model, students and parents can stay where they are and access only those services and supports they need, not the whole "package" which, in the case of special education delivered under a continuum model, almost always involves segregation.

The implementation of the current regulatory requirement that school districts must provide a continuum of services has served as a substantial barrier to achieving the overall intent of this section of the law, namely, to promote the maximum participation of students with disabilities in regular education, with removal occurring only after it has been clearly demonstrated that appropriate supplementary aids and services have failed to work. To this day, all school districts are required to have ready a series of increasingly more segregated options, including institutions.⁹ Over the years, a "continuum of services" has become equated with a "continuum of placements," the

⁹ This remains true even though some States have closed their institutions in favor of family support and supported community living options.

result being a drainage of energy and resources away from neighborhood schools into segregated settings. Ironically, the implementation of the regulations has apparently thwarted the intent of the law.

There will be situations where parents will want substantially separate placements, usually because school districts have not offered appropriate supports within the regular school environment. Other times, parents might request such placements based on the nature of their child's disability (e.g., deafness). At this point in history, such requests might be appropriate. However, this should not obstruct the overall process of rebuilding special education as a high-quality support service available in every public school building in America. The problem at present is not a lack of options to segregate students with disabilities from their peers; rather, it is a lack of options to include students with disabilities in the ongoing lives of their schools and communities.

Therefore, in order to improve and strengthen the provisions of IDEA regarding placement in the least restrictive environment, the Federal government should implement the following recommendations:

1. The goals, purposes, rights, and protections afforded under the Americans with Disabilities Act should be incorporated throughout IDEA through preambular language stating this fact.
2. The requirement that State and local education agencies must provide a continuum of services should be replaced with a requirement that State and local education agencies must provide an "array of support services designed to maximize the student's participation in regular education environments and activities." While it may be

necessary to maintain many of the current features of the "continuum" as a transition to a "supports and services" orientation takes place, and it may be the case that a relatively small number of students might continue in substantially separate placements (e.g., deaf students), the requirement that a wide array of supports and services be available in regular school buildings will better address the intent of IDEA and other legislation in eventually reducing the number of more restrictive placements.

3. State and local education agencies should be required to develop funding policies and procedures that are at least "placement neutral". That is, funds should be allocated to meet the needs of individual students, not the needs of individual programs. At least the same amount of funding should be available to support a student in an integrated regular education environment as in a segregated program.

4. Removal of a student with a disability from the regular education environment should be documented with a written report attached to the student's IEP. The written report should include: a statement of the supplementary aids and services considered, but rejected, by the IEP team; a statement of the reasons why these supplementary aids and services are not capable of assisting the child within the regular education setting; and a statement as to when appropriate supplementary aids and services will be made available to transition the student back to the regular education environment.

5. The IEP for any child with a disability who is to remain in the regular education setting should list necessary aids and services with the same specificity as the listing of necessary related services, including the time and frequency of delivery of such aids and services.

6. The Department of Education should significantly expand its monitoring and enforcement activities related to implementing the least restrictive environment requirements of IDEA. Given the extreme variability of student placement patterns from district to district and State to State, specific plans and goals for reducing the number of students placed outside of regular education settings should be developed, with receipt of future Federal funding contingent upon meeting these goals.

PARENT PARTICIPATION AND SHARED DECISION MAKING

No parent is ready or trained to be a parent of a special needs child. (Mary Ann Egger, Milwaukee, WI)

I looked for information. It wasn't there. I didn't get anything from the school districts, from any of the support people they put me in touch with. They were all bureaucrats. I got my best information from other parents, and so I think it's important that new parents, parents just coming into the system, are matched up with other parents. (Lisa Reader, Albuquerque, NM)

I have been quite a successful education story. But I think that is only because my parents are both very well educated and relatively wealthy, certainly upper middle class. And they had the ability and the knowledge to essentially face down the educational system and say, "No. You're incorrect. This is what he needs, that will not be enough," and I was able to get the kinds of services that I needed. (Dave Gordon, Boston, MA)

Despite all the wonderful changes, many parents are still not given the respect they deserve as experts about their own children. Many fathers are still left out of the process entirely. And many parents are subjected to humiliating, destructive encounters with education and health care professionals. I believe that this is because well-intentioned professionals are not sufficiently trained on how to communicate with and collaborate with parents. Accordingly, I urge that the reauthorization legislation mandate training of this kind. (Stanley Klein, Boston, MA)

Statement of Law

One of the six principles of IDEA is that parents and (where appropriate) students have a right to share decision making with educators. This principle—sometimes called parent participation or parent-educator collaboration—serves two purposes. First, it facilitates informed decisions by knowledgeable people and thereby advances the student's appropriate education in the least restrictive environment. Second, it creates a system of checks and balances, so that parents and students on the

one hand and educators on the other can hold each accountable for the student's education.

IDEA authorizes several types of shared decision making. It requires the State education agency to establish procedures for consulting with persons involved in or concerned with the education of students with disabilities, including individuals who themselves have disabilities or are parents or guardians of students with disabilities (20 U.S.C. Sec. 1412(7)); to make the State's special education plan available to the public and parents (34 C.F.R. Part 300, Sec. 300.284); to hold public hearings on the State plan and to give notice of those hearings (34 C.F.R. Part 300, Sec. 280); and to allow the public and parents to comment on the State plan before it is adopted (20 U.S.C. Sec. 1412(7)). Similar participation and consultation requirements exist for local education agencies (20 U.S.C. Sec. 1414(a)(1)(C)(iii)). In addition, the State education agency must create an advisory panel on special education, consisting (in part) of parents (20 U.S.C. Sec. 1413(a)).

Parents have the right to access the State or local agencies' system-wide records on special education, but not the records of individual students except their own child (20 U.S.C. Secs. 1412(2)(E), 1414(a)(3) and (4), and 1417 (c)). They have access to their own child's records and may restrict (to a fairly significant extent) access to those records by other individuals (20 U.S.C. Sec. 1417(c) and 1232).

In consideration of the fact that shared decision making creates opportunities for collaboration between parents and educators and that part of collaboration is the provision of related services to students and their parents or other family members, IDEA requires early intervention programs (for infants and toddlers, from birth to age 3) to fashion, with the parents' participation, an individualized family service plan (IFSP) (20 U.S.C. Sec. 1477). IDEA also authorizes some "related services" to be provided to parents if those services are part of the student's individualized education program (20 U.S.C. Sec. 1401(a)(17), (19), and (20); 34 C.F.R. Part 300, Secs. 300.6 and 300.16).

General Issues Concerning Collaboration

During the hearings, parents and students described their experiences in attempting to collaborate with school districts in various aspects of special education. Many witnesses addressed the issues of interdisciplinary and interagency collaboration.

In many schools it is still us (regular ed) versus them (special education). Students with disabilities in particular lose in this meaningless conflict. The essence of the IDEA is to move away from this mindset into one that emphasizes collaboration. (Mike Remus, Des Moines, IA)

I go to PETs with families who have children who have neurobiological disorders like my son, and I sit there and I get angry, and actually I get physically sick because I don't care what school district I sit in, what child we're representing, I hear the same comments from education professionals that [are] just plain ignorant. The things I hear about these children and heard about my own child is...that they're "unwilling," they're "manipulative," and they "don't want any responsibility," and the parents "won't take any responsibility" and a lot of negative things instead of, "Gee, what are we doing wrong [and] how can we make it right. (Cindy Sirois, Boston, MA)

Collaboration between schools and parents does not happen easily. Historically, schools have been viewed as the "experts" in education, with parents playing a minor role. To be effective, collaboration must be planned and supported, especially through training and sharing information between parents and professionals.

Training and Information Issues

Most of these parents are either unaware of their rights under IDEA, or have been pressured into accepting less than an appropriate placement for their children. Many not only do not believe their rights, but they fear retribution if they apply pressure for appropriate supports and placements. (Diana Daggett, Albuquerque, NM)

[Families] are being denied their rights through lack of being educated on their rights. (Patrick Owen, Anchorage, AK)

In our school system parent training is virtually nonexistent. Appropriate services for children cannot exist when parents are without any meaningful information about their child's participation in special ed. (Linda Speich, Charlotte, NC)

You do it yourself is what it comes down to. And fortunately, you have your rights under the IDEA, but finding out what they are and how they apply to your particular situation is entirely up to the individual parents. (David LaDue, Berkeley, CA)

There's a lot of kids that are included here locally in school primarily because of parent advocacy. So it's one child at a time. (Carl Evertsbusch, Anchorage, AK)

The PTI...has been an invaluable resource to our family. We are an educated couple, and I believe that we are relatively intelligent. However, we have needed the support and the interpretation of all the special ed language and procedures that have been thrown at us as a family, and PEAK [a PTI] has been there to provide that to us. (Ellen Laurence, Denver, CO)

To advance parents' rights to shared decision making, Congress authorized the creation of parent training and information centers (PTIs) more than a decade ago. The

PTIs are parent-directed and are responsible for providing education and training to parents on their rights under IDEA. In some circumstances, they also advocate for parents and students. There is at least one center in every State, and recently Congress authorized centers to be created on behalf of traditionally underserved or minority populations.

According to witnesses, the PTI Centers' roles are indispensable. They are the major —and sometimes the only— source for parents to learn about their children's special education needs and rights. Many parents testified that the knowledge they acquired through information dissemination and training activities of the PTIs served to prepare them to be effective in their collaboration efforts with professionals.

Witnesses had several suggestions for strengthening parent training under IDEA:

Strengthen the discretionary programs that support the parent resource centers...get information out to parents...create ways for parents to network so they can share tips and things that they've learned. (David Maltman, Anchorage, AK)

I believe we need a greater commitment to develop parent materials through interactive technology that could accommodate the various communication levels of parents and students. I also believe that...the school district should give parents information about available advocacy organizations, who may represent families in need of such assistance. (Timothy Jaech, Milwaukee, WI)

If there were any incentives for school districts to add parents to the team and either at the local, district,...or even [in] region in-service types of activities, it would be much appreciated. (Mike Remus, Des Moines, IA)

Witnesses expressed concerns regarding a lack of successful collaboration among parents, education professionals, and staff of disability service and other related service agencies across all major areas of IDEA. A sampling of their comments is provided below.

Zero Reject

The chasm between parents and the school districts is getting wider. It's not getting closer...the needs of the child are seldom mentioned during an IEP meeting: only, "School policy says..." Some schools are getting no direction on how to interpret IDEA or what it means. They have no vision for our children, nor do they have a sense of purpose. Outcomes are seldom looked at. Schools are not held accountable for the product, which is to help each of our children reach their full potential. Instead, what seems to be coming from them is to put our families through either the judicial system or the social [service] system. Either way, our families are spending their time fighting these two systems instead of raising and educating their children. (Larry Fuller, Albuquerque, NM)

Children cannot receive the education to which they are entitled unless they are first admitted into school programs. Family members testified that, much to their amazement, some children are not being allowed into schools. Their testimony illustrates how important parent participation is in the enforcement of the zero reject principle:

Two weeks ago, I saved two children from going to State custody because [their parents] were told that's the only way they could access services. There is [also] a child with MS. He has never gotten any service at all. (Michael Kidd, Charlotte, NC)

The burden...has been totally put upon me and my wife. And given that, I'd have to say God help the child that doesn't have parents with the awareness, the knowledge, the commitment, whatever it takes to do this. (Richard Curtis, Boston, MA)

Assessment for Eligibility and Nondiscriminatory Evaluation

Unfortunately, [during] his first eight years of schooling I didn't know as a parent that I had any rights or any power or responsibilities. At that time I was undereducated myself. I had a ninth grade education and I sat at PETs with people who I perceived to have the knowledge to teach my child and felt that, even though my gut told me it wasn't right, they must know. (Cindy Sirois, Boston, MA)

Parents want to be able to participate throughout each step of their child's special education process, including being a part of identifying their child's abilities and challenges. They need to be a vital part of the evaluation and assessment process.

Appropriate Education

So I ask my team each year, "What we do? Where do we go?" I did not go to college to come a special education teacher, so I look to the professionals for the answers. I've contacted my senators, my legislators, my State Department of Education, the Board of the Blind, the New England Center for Deaf/Blind Services, my local school system, including the head of special services, the administrator of special education and teachers of many special education students, and I get that same blank stare...I find the education system to be a maze of laws, paperwork, politics and bureaucrats. Everyone has a different finger to point, a new evaluation to do, another meeting to attend, and another phone call left without a response. (Catherine Reed, Boston, MA)

Individualized Family Service Plans and Individualized Education Programs

At every hearing, the importance of parents' participation in developing their children's IFSPs and IEPs was reiterated. Regulations in IDEA ensure the right to full participation for parents in the IFSP and IEP processes. However, witness after witness

offered examples of how this right is not automatically assumed and acted upon for families:

Referring to parents participating in IEPs without education or training or information beforehand: it's like showing up at a restaurant [where] you read the name over the door and you have to decide what they serve and whether we want it or not. That's about what happens at your typical IEP. (David LaDue, Berkeley, CA)

We had to endure three different staff meetings with 12 to 14 people between the spring and fall of this year before we had an adequate IEP design. The entire IEP process was not an exercise in team building nor reinforcement of our daughter's strengths. We depended on the provisions of the IDEA to reinforce our points throughout the entire course of events. I would plead that any provisions of IDEA which discourage families from playing an active respective role in the educational planning process for the children be modified. Make it perfectly clear to the educational community that families and children drive this process and not bureaucratic requirements grounded in Federal legislation. (Joe Wild Crea, Denver, CO)

I was one of those parents who left...IEPs like someone who has left a foreign movie without the subtitles. I felt a very small and incidental part of this procedure, and at times I felt a feeling that my daughter really wasn't getting her full share or placement of services. [It] wasn't until I started networking with other parents that I started feeling empowered to all the services she rightfully should have. (Diana Sullivan, Milwaukee, WI)

Parents Are Not Professionals

Parents have not received the formal education of professionals within the educational system, nor should they be forced to be professionals. Yet "becoming professional" is often part of what happens to parents:

We really need to put the responsibility again on the educators and not make all the parents professionals, because parents also have jobs, and the amount of time, energy, and emotions that every parent...has put into the education of our children's special needs [is] just tremendous. It shouldn't be that way. We really need to distribute that kind of energy more evenly. It's very frustrating. (Birgit Schweingruber, Berkeley, CA)

Parents, however, have to make a living and support a family at the same time their child is in need of a great deal of intervention. We need to find time, funding and resources to provide those parents with the on-going process of being a student, a student of being a parent of a person with a disability. (Brian Charleson, Boston, MA)

Program Methods

Many parents expressed frustration with the methods used in their children's programs. Methods such as the use of aversive procedures anger many parents, although some approve of them:

My son, with the severe aggressive dangerous behaviors that he has... improved, and he's learned and doing things we never dreamed....The quality of his life has been greatly improved by being managed on a drug-free program....I don't say that aversive is for everybody, I'm only saying that it's working for us. (Marie Washington, New York, NY)

However, many other witnesses testifying on the education of students with severe behavioral disabilities were adamant in their belief that those interventions, or other forms of behavioral, physical, or psychological control were damaging and abusive:

That following year, we had to go to due process...trying to force the school to stop using aversives on him...Tabasco sauce, vinegar, soap, paper towels down his throat, and physical restraint that was injuring him. We learned at that time that our son had been locked in a PE equipment closet throughout the winter and the spring. (Rainee Courtnege, Denver, CO)

He was duct-taped to a chair. His clothes were duct-taped on him. His shoes were duct-taped on him. (Jane Hasty, Charlotte, NC)

In the town of Cloudcroft, one kid that was classified as having ADD, was insulted by his teacher. In front of [the] whole class, [his teacher] called him stupid. That was the same week he killed himself. (Judy Bonnell, Albuquerque, NM)

When Annie was in sixth grade, she was physically abused at school by the teacher and the paraprofessional, as documented by the child abuse and

neglect team and the local police department. (Ellen Laurence, Denver, CO)

I would like to talk about adding an amendment to the Individuals with Disabilities Act that would prohibit aversive procedures, including restraints within public institutions that educate children. (Carolyn Reed, Denver, CO)

Implementation of positive behavior modification techniques was recommended as an alternative to the use of aversive and other painful techniques in the education of students with severe behavioral disabilities.¹⁰ Another witness noted the importance of modifying the environment in order to foster positive behavioral change:

Teachers [of students with] serious emotional disorders concentrate on discipline and consequences, instead of modifying the environment, which is what our children need. (Betty Cope, Albuquerque, NM)

Parent input can greatly improve educational programs for students with disabilities. However, the current system has the potential to allow parents to request and receive program methods that are unproven, experimental in nature, or dangerous or harmful to the physical or psychological health of their child. While it is possible to understand the desperation of these parents, to share their exasperation with ineffective programs and treatments, and to sympathize with them in their frustration to locate appropriate programs, there are limits to what society can permit in the name of treatment. There are those in our society who would advocate for severe physical

¹⁰ The Office of Special Education and Rehabilitative Services has funded many grants that have demonstrated the effectiveness of positive behavior change techniques over the past several years.

punishment or even the mutilation of prisoners convicted of what everyone would agree are heinous crimes. Yet these prisoners are afforded protection under the law from this treatment, even though there are those who would claim that such treatment would "teach them a lesson." Students with severe behavioral disabilities are not criminals, and yet present law allows them to be subjected to procedures which cannot be used on the most hardened criminals, or, in some cases, even on animals.

Public funds intended to provide positive educational experiences and results for children should not be expended to have these children subjected to unproven, experimental, dangerous, or violent program procedures which —by design— result in pain, physical injuries, psychological damage, hunger, social deprivation, or other such negative experiences, whether they are authorized by desperate parents or not. In any other context the use of these procedures would be considered child (or dependent) abuse or neglect. They should not be viewed as "treatment" just because a student has a disability. Under the present situation, the potential for abuse is great. Indeed, through its support of these procedures used on children with disabilities, the United States could be cited for human rights violations against people with disabilities under its own *Country Reports on Human Rights* published annually by the Department of State.

Beyond discussion concerning particular methods, parents would like to have input and give consent to teaching methods before they become a part of their child's

daily life in programs at school. Often parents' suggestions for methods are ignored or blatantly turned down as viable suggestions. Parent participation in determining appropriate education is probably one of the most neglected area in special education practice today:

My wife and I are presently even discussing her going to school with my son on a full-time basis to be in the classroom so he can receive the support he needs in order to survive in that classroom. (Steve Konecny, Denver, CO)

Parents still have to push far too much to get academic skills into the curriculum in special education, and I think more parents, because of the advocacy programs, are aware that they can push and can get things into their child's curriculum that they thought were not available. (Ginny Gilman, Albuquerque, NM)

Clearly, added training and information dissemination for parents would help them feel much more comfortable in working as partners in the determination of appropriate educational methods for their children.

Least Restrictive Environment

I know that last year I felt like I was part of a creative, collaborative team, working together to figure out what would be the most interactive environment for my son. This year, I feel like a pest. This year, I think they are doing the best they can, and so I've given them lots more information. I've given them opportunities to hear people who have done it, to be with people who know how to do the curriculum adaptations, behavior modification, whatever it is that needs to be in place for him to be a part of the setting. It's taking a while...I think that people are given the opportunity to say, "No," too often to inclusive education. (Leah Phillips, Albuquerque, NM)

The most frequent area of testimony in the area of parent participation was the principle of the least restrictive environment and the movement for inclusion of children into regular education classes with supports. Many family members gave compelling stories of children's successes in inclusive environments. Some argued for a continuum of services. However, regardless of their perspectives, one point that came across loud and clear was the parents' desire to participate in decisions and to have their wishes heard and respected when professionals are deciding upon their child's placement in a special education program.

My daughter is eleven years old. She's autistic, mentally retarded and up until last year...was in self-contained classrooms. Last year we decided to attempt inclusion with lots of support through our UAP and our local school district. Kara had a remarkably successful year. We saw more progress in that one year of inclusion than we saw in six or seven years of very intensive one-on-one special education... (Kathleen Fitzgerald, Anchorage, AK)

Procedural Due Process

Witness after witness testified that procedural due process is one of the most important provisions of IDEA, as it is the avenue that allows parents to enforce their participation in their child's education. Without this part of the law, special education would not have produced its successes to date. Still, parents testified about problems in exercising this right:

A child's right to a free appropriate public education should not depend on the parent's ability to advocate for it. (Sue Endress, Milwaukee, WI)

I found that in signing my son into special education, I might [have] just as well signed away all my parental rights, as well as signing away my son's rights as a human being. (Dawn Gloss, Des Moines, IA)

Recommendations: Parent Participation and Shared Decision Making

Parent and student participation and collaboration in the design and delivery of special education services is essential, if these services are to be relevant and effective in maximizing a student's academic and social development. Congress was wise in its decision to include many avenues for parent and student involvement in the special education process and these requirements have resulted in a better quality of education for thousands of students. However, many shortcomings in this area continue to exist. In order to address these shortcomings, the Federal government should implement the following recommendations:

1. Expand funding for the Parent Training and Information (PTI) program. PTIs can (and often do) serve as the primary information source for parents regarding special education and offer a cost-effective method of providing this information to parents and family members.
2. Require State and local education agencies to provide parents of students receiving (or being considered for) special education with the name, address, and telephone number of the PTI serving their area. This could be far more cost effective for school districts and would result in improved comparability of information across the State.
3. Parent input can greatly improve educational programs for students with disabilities. However, the current system has the potential to allow parents to request and receive program methods that are unproven, experimental in nature, or dangerous or harmful to the physical or psychological health of their child. Accordingly, there should be an additional State Plan requirement which would require States to certify that no Federal funds will be used to support any individual, program, or practice that employs procedures such as systematic hitting or physical punishment, the application of noxious substances, extended restraint or seclusion, humiliation, and other techniques which —by design— result in pain, physical injuries, psychological damage, hunger, social deprivation, or other harm, that would otherwise be considered as constituting child (or dependent) abuse or neglect if the student were not disabled.
4. The Department of Education should review data regarding the use of surrogate parents under IDEA in order to determine the frequency of use, the roles that surrogate parents actually assume in special education, levels of satisfaction of surrogate parents

regarding their experiences with the special education system, and ways to support surrogate parents more effectively in their efforts to provide effective representation for students receiving special education.

PROCEDURAL DUE PROCESS

Statement of Law

For those who pioneered the right-to-education doctrine, the procedures for implementing the right were as crucial as the right itself. Procedural due process is a means of challenging the multitude of discriminatory practices that the schools had habitually followed. It also is a way of enforcing the first four principles of IDEA and putting them to work (zero reject, nondiscriminatory evaluation, appropriate education, and least restrictive environment)....Procedural due process—the right to protest—is a necessary educational ingredient in enforcing every phase of the disabled child's right to an education. (Turnbull, 1994, p. 207¹¹)

IDEA endeavors to ensure procedural due process in a multitude of ways:

- ◆ It requires education agencies (1) to secure parental consent before initially evaluating a child for special education placement or placing the child in special education; (2) to notify parents in the parents' native language or in other effective ways whenever they propose to change or decline to change the student's placement, evaluation, identification or appropriate education; (3) to consider independent evaluations of the student and, in some circumstances, to pay for those evaluations; (4) to appoint surrogate parents for students whose natural parents are unknown or unavailable and for students who are wards of the State; (5) to establish procedures for administrative due process hearings and for appeals to the State agency (after which lies appeal to a Federal or State court); and (6) to follow a "stay-put" rule that generally requires education agencies to leave a student in the student's present educational placement and program during the due process hearing and appeals (20 U.S.C. Secs. 1415(b) and (e), 1480(6)).
- ◆ IDEA also allows (but does not require) State and local education agencies to offer mediation in order to resolve disagreements between the agencies and parents.
- ◆ IDEA allows parents to recover their attorney fees if they prevail in a dispute against a State or local educational agency (20 U.S.C. Sec. 1415(e)). These fees may be awarded for attorneys' participation in mediation, due process administrative hearings and appeals, and court proceedings.

¹¹ Turnbull, H.R. (1994). *Free appropriate public education: Law and education of children with disabilities*. Denver: Love Publishing Co.

- ◆ Finally, IDEA establishes various other enforcement mechanisms, including State assurances of compliance with IDEA if it receives Federal funding and procedures for Federal monitoring of State compliance and withholding of Federal funds when a State is out of compliance with IDEA (20 U.S.C. Secs. 1412, 1413, 1414, and 1416).

In short, procedural due process is both a constitutional guarantee and a statutory right that Congress has fashioned as a comprehensive means for enforcing IDEA (Smith v. Robinson, 468 U.S. 992 (1984)).

Throughout the hearings, witnesses stated their distress about IDEA's enforcement and their belief that while IDEA's due process provisions are absolutely necessary, their implementation has been very problematic. Most of all, witnesses expressed resentment that they had to use due process: Why, many wondered, should they have to use due process to secure their children's rights guaranteed under the law? Shouldn't schools have to comply with IDEA?

Enforcement in General

I have come to the conclusion that I'm just not going to fight anymore. But I came today to let you know that your laws are not being followed through. (Marie Bauer, Milwaukee, WI)

We don't need more laws regarding educating children with disabilities; what we need is enforcement of the laws that are already on the books. (Christine Multra Kraft, Milwaukee, WI)

I think the issue is enforcement. Currently, with the law in Illinois, we file complaints with the Office of Civil Rights, and nothing ever gets done. We end up having to go to court. (Rene David Luna, Milwaukee, WI)

IDEA is a beautiful law. However, with the State and local education agencies' disregard of its most basic premises, it has not as yet become the law of the land. (Wendy Luckenbill, Philadelphia, PA)

More than two dozen witnesses testified that enforcement was critical to the success of IDEA. Their unanimous consensus was that, if the provisions of IDEA were enforced, due process hearings would be rare and the quality of education for children with disabilities would be greatly improved. All the witnesses who discussed procedural due process offered general ideas how enforcement could be improved:

- ◆ Dianne Taylor Owens testified that monitoring is needed to make sure children are not *falling through the cracks* (Albuquerque, NM).
- ◆ Janis Symanski advocated for monitoring through government agencies and the need for accountability of the qualifications of professionals (Boston, MA).
- ◆ Judy Gran stated that enforcing the law under the IDEA is extremely difficult. She added that if the State does not adequately enforce the requirements, then students and parents have little recourse (Philadelphia, PA).
- ◆ The March family recommended that an enforcement agency similar to the Occupational Safety and Health Administration be established to oversee school programs and impose penalties if needed (Des Moines, IA).
- ◆ Dee Estelle Alpert and Edris Klucher stated that the only way to achieve implementation of IDEA by the Office of Special Education Programs is to impose financial penalties for violations (New York, NY; Albuquerque, NM).
- ◆ Like Alpert and Klucher, Jean Parker of Denver also wanted a strict financial penalty for violations. She recommended that the Federal government take back all special education funding when a State does not comply with IDEA (Denver, CO).
- ◆ Maureen Hollowell agreed that Federal support should be discontinued if States violate IDEA (Philadelphia, PA).

- ◆ Nancy Baesman stated that increased enforcement from the Federal level would be more effective in bringing about change than parents using due process (Denver, CO).
- ◆ Beverly Roberts recommended outside monitoring to ensure compliance (Charlotte, NC).

Six other witnesses generally agreed that some sort of monitoring is needed and that without enforcement, the law has "no teeth." They all stressed enforcement as the key to a successful law. However, four parents testified that there was no enforcement even after due process had determined that there were violations. One of them testified that even after a school district had been found to be in violation of several laws, nothing happened to the district (Bonnie Weninger, Milwaukee, WI).

Other witnesses stressed the importance of parents knowing their rights and using them. Maureen Hollowell recommended one method parents can use to enforce IDEA. She said that she finally succeeded when she exercised her rights by refusing to sign the IEP until it provided an appropriate education for her child (Philadelphia, PA).

In sum, the parents who testified about enforcement were adamant that without monitoring and enforcement, IDEA will not be followed and individual due process attempts at securing enforcement will be futile for purposes of systemic change. Parents who have used due process complain that the victories are few, and when they do occur, the remedy is limited to that case and does not automatically cause positive changes to be implemented throughout a local or State school system.

The due process system may be adequate to resolve many discrete and simple issues, such as the student's classification or the amount or duration of services, but it cannot resolve systemic disputes. For example, disputes over inclusion, over the quality of instruction and over the adequacy of teacher training. The difficulty for parents in obtaining more changes in the system through the process is only reinforcing the status quo. (Judy Gran, Philadelphia, PA)

The general attitude of the witnesses was that parents and the Federal government must band together to ensure accountability in State and local agencies.

Due Process in General

Parents acknowledged that due process hearings were essential to enforce the rights of their children:

It's clear that without this safeguard, our son would have been relegated to a separate classroom for students with multiple disabilities for his entire schooling. (Barbara Buswell, Denver, CO)

Some parents were able to use the due process right as a threat to make the schools more responsive. Other parents testified that due process is more than a useful threat: It is, instead, a reflection of the adversarial stance that parents are often forced to assume when trying to work with educators. Indeed, many parents expressed dismay that schools had forced them to resort to due process:

Why do people have to go through what they go through to get the changes so that their child can benefit from a free appropriate public education? That's the sin that I see...Yes, due process protection does work, but the cost to families, emotionally, is not fair. (Amy Goldman, Philadelphia, PA)

I looked under the table. I actually was grabbing for a pen out of my briefcase yesterday, and found that the classroom teacher had placed under the table a tape recorder. I said, "Jim, what is that?" And he said, "Well,

I'm protecting my civil rights." We've tried to work as partners with our teachers and principals, and in fact, I think that we have been extremely gentle in our approach most times, because I myself was a teacher for many years...But it was that teacher's interpretation of the law: that it was his rights that were being protected here, and that as parents, we were just pushy, unreasonable professionals rather than people who were very concerned about our child's outcome. (Mary McDonald Richard, Des Moines, IA)

Often families choose to ignore or forgive violations and try to move forward to achieve a free appropriate public education for their child. While I fully understand the decision to let bygones be bygones, and often support families who make those decisions, this distorts the reflection of violations when one looks at the body of complaints filed with the State education agency. (Maureen Hollowell, Philadelphia, PA)

Due process is accessible to those parents who have been able to learn the rules, and who have the emotional, intellectual and financial resources to take advantage of protection afforded them under the law and withstand the process. Thus, children with disabilities, of parents who are poor, or minority communities, have other family stress or have limited English proficiency, continue to be disenfranchised. (Amy Goldman, Philadelphia, PA)

Look at the enormous waste of time, money, and most importantly, the educational experience for my son. I do not have time to wait until tomorrow and tomorrow for my son to get the appropriate education he deserves. (Karen Robard, New York, NY)

Parents viewed the complaint and due process provisions in IDEA as a double-edged sword. Approximately 80 parents gave testimony regarding their frustrations with the due process aspects of obtaining a free appropriate education for their child. In general, however, they viewed due process hearings as necessary tools for bringing about the desired and intended benefits of IDEA.

Martha Beebe, a parent who also is a teacher, went through due process to get her child's IEP changed. It took ten months (rather than the mandated 45 days) to get a final decision: an entire school year. She stated her belief that the IDEA is full of promise, but must be enforced to become more than empty words on paper (Beebe, Boston, MA). Other witnesses underscored the need for due process and improved enforcement, a need created by school districts' reluctance to implement the provisions of the law properly:

I have come to call myself "Bonnie the bitch" because of what I have had to become to fight the system...I have contacted multiple State offices. I have followed through with every lead that anybody has ever given me. I have talked with the Governor's office here in the State. I have gone so far as to call the White House...I guess my feeling at this point is, is there anybody out there who really cares? I don't know what more to do. I, as a parent, have pursued every option. (Bonnie Weninger, Milwaukee, WI)

We have a teacher who refuses to follow an IEP. And then that's when the psychologist and the principal just throw up their hands and look at me [and say], "Well, we can't make her do it." And that is very frustrating. (Jill Rigsbee, Charlotte, NC)

Until the Federal government compels States and cities to comply with its mandates, IDEA will remain a haven for the few. (Walter Theis, New York, NY)

Witnesses stated that minority families (especially Native Americans) with children with disabilities often do not pursue due process or even get to the mediation process because of language barriers or cultural factors. Moreover, it was reported that many Native American parents with children who are not receiving needed special education services have relatives who work for the Bureau of Indian Affairs. Because of

this, they do not complain about inadequate services because it may negatively impact upon their relatives. (Martha Johnson, Albuquerque, NM)

At every hearing, parents expressed fear over retribution and retaliation by the schools if they exercised their due process rights. In one situation, a parent reported that although she won a court battle to have her little boy placed into an inclusive kindergarten, the LEA retaliated by providing only narrow, technical compliance with the decision. The child was physically put into classroom where the teacher effectively segregated him by placing him in the back of the class and not allowing any real participation with the other children (Eleanor Voutsinas, New York, NY).

Another mother described her experience in attempting to exercise her due process rights as follows:

When you have to advocate for your child, you pay a high price for that in many ways. It's very stressful on the family....Because of the kind of advocacy work that I've had to do...I'm not able to teach anywhere locally. I actually teach school in Texas, which is a 30-mile drive in the time difference away from my home....My son suffers from bipolar disorder and numerous other difficulties. That illness itself is stressful, but when you have a vindictive, harassing, retaliatory school district to deal with, it makes your life completely miserable...that's what I've had to deal with. (Edris Klucher, Albuquerque, NM)

Unfortunately, retribution (or fear of retribution) is an issue. Indeed, one parent told how schools can use the "stay-put" provisions under due process to effectively impair students' rights. After expelling a student, a school then initiated a due process complaint, causing the child to be kept out of school one entire year during proceedings.

Due process is not working in my area. The stay put law is generally ignored, or the parents are urged to drop the children from their class. In my case...my son was kicked out of school completely. (Ann Williams, Denver, CO)

A lot of parents don't want to make waves. They don't want to say anything because it makes it worse on their child. Indeed, it does make it worse on the child. (Beth Gage, Philadelphia, PA)

When you have to advocate for your child, you pay a high price for that in many ways. It's very stressful on the family...when you have a vindictive, harassing, retaliatory school district to deal with, it makes your life completely miserable...that's what I've had to deal with. (Edris Klucher, Albuquerque, NM)

One mother, whose 15-year-old son with autism was moved out of a high school into a school for younger students (because there were "more openings" in the school for younger students) with only a one-week notice described her experience with due process as follows:

Throughout the due process, we were given notice about meetings practically at the last minute. No one encouraged us to bring an advocate to help us. There were people at the meetings who we did not know and who did not have any involvement with our son, particularly at the school-based level....The administrator in charge of handicapped students here in Charlotte told us that we could be arrested for truancy because we refused to place our son in a class, [when we] were not involved in the decision on change of placement. (Rachel Friedman, Charlotte, NC)

Moreover, due process, while necessary for many purposes, does not solve all school issues. In recounting the story of how her 14-year-old adopted son Adam (who has multiple disabilities) had been repeatedly battered and abused in school, Bonnie Weninger of Lomira, IL said she finally called the police, who informed her that there was nothing they could do.

I find out now, years later, that...our police departments have no jurisdiction to come into the public schools, that the only way I could have initiated an

investigation was to hire private legal counsel, and I didn't. I didn't know that or I would have done that. (Bonnie Weninger, Milwaukee, WI)

Despite the problems the parents identified, they approved of all procedural safeguards, especially notice and the ability to obtain an independent evaluation.

As a minority person I'm really thankful for the independent evaluation in the law, because it does allow parents sometimes to have assessments by people who understand the child's culture. (Virginia Richardson, Des Moines, IA)

In making recommendations, witnesses called for better training and the appointment of independent¹² hearing officers to ensure impartiality. They advocated for stronger enforcement of the general provisions in IDEA, without fear of retaliation. Finally, they said that they do not want the general fear of violent behavior in the schools translating into harsher rules for children whose behavior problems stem from disability.

Mediation

By the time mediation comes and goes, the child is facing placement for the next year, and the process begins all over again. (Tammy Stuck, Denver, CO)

More than two dozen parents gave testimony regarding mediation as an alternative to formal procedural due process hearings. In general, they expressed many of the same concerns about mediation as they did about due process hearings.

¹² Several witnesses complained that in their experience, hearing officers were not impartial as they were being directly paid or trained by LEAs or SEAs.

One problem relates to the appearance of bias:

The mediation process was no more impartial than any of the other meetings the district had orchestrated. Mediators are trained by the Colorado Department of Education and are neither perceived to be nor are they...impartial third parties. In the reauthorization of IDEA, I hope to see the mediation process changed so that mediators will indeed be disinterested and unaffiliated third parties. (Marna Ares Thompson, Denver, CO)

Mediation needs to be "delegalized" as much as possible with parents feeling that they are in neutral territory and dealing with objective individuals. (Carol Gonsalves, Berkeley, CA)

Other concerns related to the issuance of "gag orders" on parents, the absence of official records of proceedings, and lack of follow through with mediated agreements.

Rarely does a hearing officer render a decision. My feeling on that is the school districts are sweeping their violations under the carpet. Parents are being placed under gag orders in order to get their children the appropriate services that they need, so parents can't even talk about it. (Bonnie Weninger, Milwaukee, WI)

One parent moved out of her school district because, although the district agreed to provide the inclusive setting she was seeking through mediation, the district threatened to make her go to court the next year (Marna Ares Thompson, Denver, CO). While witnesses generally distrusted the mediation process, they also saw it as a possible opportunity to resolve complaints with schools without incurring even more costs and the questionable results of protracted administrative or judicial processes. They viewed mediation as a viable option as long as they were not forced into it and as long as they were made fully aware of their rights, including the option of proceeding to formal due process hearings if necessary. Finally, some witnesses called for more clarity about mediation procedures, especially guidelines for appointing neutral third-party mediators.

A few parents suggested a process of binding arbitration as the solution to problems with mediation.

Attorney Fees and Attorneys

The attorney fee provision in the law is necessary to ensure protection for all parents. (Kris Christenson, Des Moines, IA)

The whole point of having due process at the administrative level is to keep it out of the courts. But with this present situation, you are literally forced into the court system at a higher level to get attorney fees reimbursed. Attorney fees must be awarded at the administrative level, if parents are going to be afforded their rights under IDEA. (Nancy Baesman, Denver, CO)

The fact of the matter is, if you're under the poverty level, you're more worried about putting beans in your belly and clothes on your back. It's not as important. But [even] the people that can afford an attorney can't find one, and so we're in a real hard spot. (Larry Fuller, Albuquerque, NM)

Witnesses agreed that provisions regarding the award of attorney fees were greatly needed, but they disagreed on whether current provisions were adequate.

Julie Doy, Cheryl Johnson, and Denita Swenson in Des Moines; Rick Tessandore in Anchorage; Lisa Reader in Albuquerque; Donna McNulty in Philadelphia; and Dave Gordon in Boston discussed how and why attorney fees were needed to help families advocate for their children. Other witnesses discussed their experiences with the issue of attorney's fees:

- ◆ Bonnie Weninger in Milwaukee complained that her attorney fees exceeded what she paid for her home.

- ◆ Jan Serak in Milwaukee testified on behalf of parents who cannot afford an attorney, stating her belief that an attorney should be provided for them at public expense.
- ◆ Janis Symanski and Robin Ann Tracy in Boston testified about the needs of the economically disadvantaged and stated that without assistance, attorney fees and costs are deterrents for many needy people.
- ◆ Judy Plzak in Philadelphia testified that the threat of attorney fee awards by courts can be a strong inducement for school districts to avoid protracted due process confrontations.
- ◆ However, Patty Jennings in Albuquerque testified that schools are not generally threatened by the possibility of due process because they know that many parents cannot find low-cost legal services.
- ◆ Nancy Baesman in Denver expressed concern that the cost to bring a complaint at the administrative level was a deterrent to parents, because some people believe that attorney fees are only awarded at the judicial level. She also noted that parents' costs are increased, since it is necessary for them to return to court to collect fees after winning the case. Indeed, the length of time before reimbursement can ruin a family's finances:

What I have found to be the primary reason for parents not pursuing due process is the cost. They simply cannot afford it from the beginning, or they cannot afford the risk of losing their investment. I have known many families who will compromise with the school district or will simply pull their child out of the situation and pay out of their own pocket for whatever they need. The school districts play on that theory and usually come up the winner.

- ◆ Jim McGovern in Milwaukee and Pam Ormsby in Berkeley expressed concern over the general assumption that all parents can afford attorneys or qualify for legal aid. Mr. McGovern also voiced the sentiment of six other witnesses that there is a great need to train lawyers in special education law.
- ◆ Mary Schoonmaker in Denver agreed. She credited attorneys in the field as helpful, but stated that most people cannot afford qualified attorneys.
- ◆ Denise Kring in Boston observed that the present system is lengthy and costly, and that it is very difficult to find a helpful attorney.

Nolan Rappaport is a parent and an attorney in Potomac, MD. His 16-year-old daughter has autism, severe developmental delays, and epilepsy. Although he is an attorney and has done much of the legal work advocating for his daughter, he has spent over \$30,000 for necessary assistance from another attorney who specializes in disability education law. He has two cases in administrative proceedings and two cases before the United States Court of Appeals for the Fourth Circuit concerning his daughter's educational rights:

If a parent with my resources and determination gets this battered by the system, what happens to the parents who can't fight a government institution the way I have? How do they get the education that their handicapped children so desperately need? (Nolan Rappaport, Philadelphia, PA)

Finally, Larry Fuller in Albuquerque stressed the need for training attorneys. He stated that very few attorneys have the knowledge necessary to represent parents and students properly. He explained that in Albuquerque, all the attorneys with training have already been retained by the State, because the State can afford to pay them more than parents and students. As a result, parents and students are left at a great disadvantage.

Other witnesses also spoke of problems in accessing attorneys:

I really feel there's a kind of de facto discrimination in terms of enforcement of the law. And I see again and again that parents with money and parents with education and parents with time are able to get a...different level of service for their children. (Pam Ormsby, Berkeley, CA)

Without known exception, the school districts are well represented in all cases where a child's rights are in question. The scales of justice are heavily

weighed in favor of the institution over the individual with disabilities. What this means in practice is that parent without legal skills attempt to match wits with the experienced attorneys. All too often they fail, not because their cause is wrong, but because they lack the representation that is provided by the taxpayer for the institutional opponent...Even prosperous parents seeking counsel to represent their child in special education matters have difficulty locating experienced attorneys. We know of an instance where 20 unsuccessful attempts to secure an experienced attorney were made. When [protection and] advocacy [services] took on the case, the parents prevailed on each and every issue presented. The reason the parents with the means to pay couldn't secure private counsel with expertise in special education issues is that almost invariably the private attorneys who have acquired such expertise are attracted to the school districts where they can earn higher wages. (Denita Swenson, Des Moines, IA)

Recommendations: Procedural Due Process

Most of the problems regarding the implementation of the due process provisions of IDEA reported by parents during the hearings can be traced back to a lack of monitoring, enforcement, and sanctions for noncompliance on the part of State education agencies and the Federal government. Simply put, if there are no sanctions imposed for noncompliance, and if noncompliant activities continue to receive funding, then noncompliance will be the rule, not the exception. In order to ensure that procedural due process rights are protected and strengthened, the Federal government should implement the following recommendations:

1. Improve and strengthen Federal monitoring and enforcement activities. Under plans for the "reinvention" of Federal processes and procedures, the Department of Education should adopt proven methods of field audit for compliance developed under quality control monitoring mechanisms in the private sector. A major measurement variable in these audits should be customer satisfaction with services. Sampling of customer satisfaction should go beyond State capitals and include visits to less populated and rural areas.

2. Encourage all States to adopt similar audit procedures in their monitoring of local education agency compliance with the provisions of IDEA.
3. When State education agencies are found to be in noncompliance with the provisions of IDEA according to these revised audit procedures, plans for achieving compliance should be developed in an expeditious manner. These plans should include specific remedial actions to be taken, timelines for implementation, and a statement of the potential financial impact for continued noncompliance. Audit findings and plans for compliance should be forwarded to the chief State school officer and the Governor.
4. Encourage States to allow parents and students the voluntary opportunity to seek mediation prior to engaging in full-fledged due process procedures. Mediators should be independent, with no real or apparent conflict of interest with either the local school district or the State education agency.
5. Explore the possible use of binding arbitration as another method of nonlitigative dispute resolution.
6. Prohibit retaliation by State or local education agencies (or their assigns) against parties seeking to exercise their rights under the due process provisions of IDEA¹³
7. Establish effective procedures for final appeal to the Secretary of Education in matters which have not otherwise proved resolvable and publicize the results of these appeals.

¹³ Retaliatory actions are prohibited under the Americans with Disabilities Act, Section 503. Similar provisions could be incorporated into IDEA.

TRANSITION

Statement of Law

Special education encompasses many services that are important to students with disabilities, but no service is ultimately useful unless students are provided with effective transition services as mandated by IDEA (20 U.S.C. Sec. 1401 (a)(19) and 20 (D)).

The process of planning for the transition from school to adult life is a critical right and component of IDEA. The skills learned in the school setting mean very little unless they can be useful in adult and community life. (Gwen McCollum, Des Moines, IA)

Transition services are a set of activities coordinated with parents, students, school personnel, and community agencies. They are designed using an outcome-oriented process to promote a student's successful movement from school to post-school activities that are comparable to those in which students without disabilities engage (20 U.S.C. Sec. 1401(a)(19) and 20 (D)).

Throughout the public hearings two major themes emerged on the topic of transition: transition services and planning should span across a person's entire life, and changes need to be made in the transition planning process. In addition, the theme of collaboration pervaded the testimony: Increased and mandated collaboration between parents, students, adults with disabilities, schools, and service agencies is necessary for a student to receive effective transition services.

Transition Across a Person's Entire Life

Witnesses argued that the mandatory age for transitional planning needs to be lowered, that schools can and should do a better job of preparing students for post-graduation success, and that grade-to-grade transition planning should be improved.

The Mandatory Age for the Initiation of Transition Planning Needs to Be Lowered

Early identification of needed transition services will allow the student more time to acquire the necessary skills for a successful transition from school to post-school activities. (Kelly Davis, Albuquerque, NM)

Children are children for a relatively brief period of time. They become adults for three quarters of their lifetimes. So each child, regardless of ability, needs to prepare for those adult years as early as possible, and in the case of many of us with disabilities, the preparation will take a bit more planning. (Suzanne Bacal, Philadelphia, PA)

Transition plans need to be implemented at any time and shouldn't be viewed strictly as a function of age. (Ellen Laurence, Denver, CO)

IDEA requires that transition services begin no later than age 16. However, adults with disabilities, parents, and family members at the hearings said that these services need to be provided, at the latest, by the student's first year of high school because it often takes more than two years for students to develop effective transition skills (assuming students exit school when they are 18). Because the goal for special education is to provide the life and academic skills necessary to function as independently as possible after school, students have to receive their training as soon as possible.

We had a consultant who, when Rick was in the eighth grade, kept very persistently saying to me, "We need to talk about what Rick is going to do after high school." My reaction at the time was, "I do not want to talk about that. I'm trying to get through this week. I'm trying to get through this day. I do not want to talk about four years down the road." What I didn't tell her was that it scared me half to death to think what that might mean. But very persistently, very doggedly, very non-judgmentally she pushed and pushed until finally out of exasperation more than anything else I threw up my hands and said, "Okay, let's talk." Through some very concerted efforts by the planning team, Rick moved into a transitional living program June 13, 1987. Rick left home. That was the first thing he had done developmentally on time his whole life. (Deb Sampson, Des Moines, IA)

The student's needs, interests, strengths, and abilities must be the basis for transition goals and objectives, and these must be very positively tied to adult outcomes in a very clear way. Supports must be truly individualized. Students must not be lumped in transition programs where everyone between the ages of 19 and 21 is getting the same thing. Otherwise you have the same situation you have at a younger age where a label drives services. We don't want transitions to drive services. We want needs and abilities to drive services. (Judy Martz, Denver, CO)

Opinions varied as to how soon transition planning should begin. Some parents advocated for starting as early as the first or second grade, while others believed that middle school might be an acceptable time. Regardless, every witness said that the eighth grade or the first year of high school was absolutely the latest time when transition planning should be initiated.

Transition planning is not occurring in a manner and probably as early as it should....Right now, what's happening is that our kids are graduating from school, and they're dropping off and going into oblivion. (John Foley, Albuquerque, NM)

Witnesses described many potential benefits from an earlier transition planning process. First, it would help students put their current education into perspective.

Their high school classes might seem more relevant if they could understand just how the classes would assist them beyond the walls of the school. Of course, this assumes that classes allow the student to transfer high school instruction to practical use in the community after high school.

We adults have the responsibility to guide children on the correct path, and when we don't, what kicks in is welfare or homelessness or crime or institutionalization. With proper, systematic, individualized transitioning, what we get is contributing, participating adults who take personal responsibility rather than expect[ing] to be taken care of by parents and the government. (Suzanne Bacal, Philadelphia, PA)

Second, it may take several years for students to master certain college preparatory, work, or life skills before they are able to function independently outside of school. Earlier transition programs will allow students to graduate and assimilate into the community at age 18 or 21, instead of requiring that they spend more time after school ends attempting to develop new skills.

Now, most folks age out [of special education] at age 22. The fact is that they age out and a lot of them come out of school. They don't have a job. They are not expected to do much when they leave. So they sit home for two or three years unless somebody has, to use the colloquial term in my city, "hipped them" to us or passed them to us... Then they come to me and I'm saying, "Let's do this....Are you registered to vote? Have you gone to RSA and tried it? Do you know what the process is?" Most of the time, the answer is, "No." So I'm having to do work to back track for what I think schools aren't giving these students. (Greg Dougan, Philadelphia, PA)

One of the problems that students have with post-secondary education is they're scared to death of coming out to campus. They are just flat bottomed frightened; and one of the reasons the students are so frightened [is that] they have some real difficulties with self-esteem. They have difficulty at valuing themselves and being able to take challenges that other students just naturally take on and are encouraged to do. They've been beaten up, and I don't know how else to put it. They've been beaten up because they have limitations, maybe a physical limitation, maybe an emotional limitation, but

whatever the limitation, they had to learn to integrate there, and it hasn't been a pretty process. (Fred Greasby, Milwaukee, WI)

Third, many transition programs are not available to students once they leave the school setting. Thus, their development could be interrupted before it is completed, and they are left to function in a new environment without the appropriate knowledge and skills.

Finally, extra time for transition will allow the schools and parents to create a long-term program focused on helping students acquire the skills needed to live independently. Students usually require more than two or three years to transition to independent living.

High School Programs Can Better Prepare Students for Success Following Graduation

Most young people with disabilities want the same things as their peers: getting a job, earning money, staying off welfare. With the proper information and guidance, these young people can realize their dreams. (Debra Titus, Charlotte, NC)

If we don't provide those transitional benefits to young people, then it's not going to be beneficial to anyone. The bottom line is...the reason our students go to school is like all of us, to learn a trade, to learn to go out and work. All my daughter is saying [is], "I want a job in this community. I want to be accepted by this community. If I'm not accepted, what's going to happen to me?" (Rose Marie Sanchez, Albuquerque, NM)

In order to maximize a student's potential in a postschool setting, the link between high school and the "real world" needs to be strengthened. Students should not be abandoned once they have been provided with some transitional services. Supports

provided after graduation can guarantee that the skills learned in school will not be lost in new environments. At present, there are two options for students following graduation: finding employment or continuing their education. High schools can provide programs that make pursuing these choices realistic and viable. Usually, a joint effort between high schools and employers or postsecondary programs offers the best opportunity for success.

On the whole, there can be little doubt that John was better prepared for adult life as a result of IDEA and the opportunity to receive a free, appropriate public education. (Gwen McCollum, Des Moines, IA)

Before IDEA's transition provisions were enacted and implemented, most students with special needs did not dream of continuing their education. If they wanted to work, it usually meant being placed in a sheltered workshop where they performed menial labor with other persons with disabilities for extremely low wages. Their skills were never fully developed, with the result that they remained segregated from a world where they could work with some training.

If [continuing education] becomes the norm, those students who age out will get the same educational help and the same requirements that able-bodied students get right now, which is, you are a student for the rest of your natural born days. You learn until you die. (Greg Dougan, Philadelphia, PA)

Edward Weinstein, a former special education student, reported that he is now living independently, voting, preparing his own taxes, and working. His accomplishments have far exceeded what professionals had projected earlier in his life.

One day I hope that doctor that said I couldn't expect Ed to be anything more than a delivery boy (and I don't mean this in a denigrating way) finds out what a

wonderful useful, helpful man Ed has grown to be. He's surely a success story from special ed. (Marilyn Weinstein, New York, NY)

Although only a few adults with disabilities or parents testified that they or their children attend a postsecondary school, students with disabilities are provided more opportunities to do so today. Stronger programs in the schools will ensure that their talents are cultivated as they enter work places and campuses. Rarely do parents and children think that postsecondary education is an alternative. This could be attributed to a lack of information concerning programs or a fear of failure in a new and strange environment.

One option for schools is to expose students to junior colleges and universities while they are still in high school. A program in Milwaukee brings special education students to a junior college for a day and allows them to see what college life is like. Familiarity is the key to encouraging students to pursue a postsecondary education. Trained personnel at both the high schools and postsecondary institutions help students apply to college and then create a college course schedule.

One student has experienced college campus life in Colorado Springs, Colorado. He and his family decided that he would benefit from graduating from high school at age 18 with the rest of his peers, but he still received services from the school district through an IEP and an ITP. After his first year, students from a fraternity on campus invited him to join their fraternity. What once was considered unachievable became a

very realistic opportunity, of which he took advantage. These impressive results can be traced to his early exposure to the campus.

Many families and students perceive the cost of college to be an impossible obstacle. Family members testified that they had already spent large sums of money in acquiring a better education for their children in special education programs, indicating that they need information concerning the types of postsecondary financial aid available to them. Testimony reflected that the level of financial aid awarded to students with disabilities at the university level was disproportionately low when compared to the rest of the student body. Increased information from postsecondary programs would provide more students with disabilities with opportunities to access financial aid.

Another aspect of establishing stronger links to life after school is job training. Allowing students to learn job skills while still in school makes them employable upon graduation. In New York City, funds are available to local merchants who employ students from special education programs. The program simply reimburses the employer the amount of wages earned by the student. The student is able to work in his neighborhood instead of a sheltered environment, earning at least minimum wage. The student gains valuable work and social skills while at the same time learning the benefits and rewards of working. The employer, on the other hand, gains both extra productivity and valuable experience in employing a person with a disability, often

changing coworkers' and customers' negative attitudes toward individuals with disabilities.

Parents expressed fear that once the student leaves the school system, supports will disappear and they and their young adult will be stranded. This fear can be addressed in two ways. First, extending mandatory transitional services beyond graduation will ensure that the student will not be forgotten. Second, more information on services should be made available to parents and students.

Grade-to-Grade Transitions Are Also Important to Students' Success

Transition is so much more than moving from public school to adult services. It's from grade to grade and school to school. Because IDEA allows flexibility to schools in implementing IEPs, children lose continuity that is so important to success. (Jerri Miller, Denver, CO)

Transition from infant learning into the school system somehow has to be managed more appropriately so that it carries forward that family focus: that the family retains what they've learned about their child and [continues to be] seen as an expert. (David Maltman, Anchorage, AK)

Mandated transition services focus primarily upon the move from high school to postschool activities. There are, however, other transitions throughout the entire education journey: from infant and toddler programs to preschool and kindergarten; from primary school to middle school; and from middle school to high school. Inadequate provisions for transition at any of these stages can restrict students' potential and negatively affect their performance for the rest of their academic careers.

Testimony indicated that early intervention (also known as "Part H") programs for children aged birth to age 3 are extremely successful. These programs are based on the premise that when infants are tested early, and if they and their families receive needed services for any diagnosed disabilities, they will have a much higher probability of success in school. It can be very difficult for a child to make the transition from Part H services into the school system. If it is not done properly, the results for the child and the family can be detrimental. While Part H is not a transition statute *per se*, the successful transition from Part H to school services can maximize a child's potential.

Another strength of Part H is found in its family-centered focus. Unlike virtually every other Federal law, Part H focuses on the entire family, not solely upon the needs of the child. The focus on family strengths has a direct impact on the child's success in early childhood and beyond. In addition, the State-level Interagency Coordinating Councils (ICCs) required under Part H provide a vehicle for exemplary collaboration among the many agencies involved in comprehensive services to families of infants and toddlers with disabilities.

The emphasis on coordinated services to and participation by families distinguishes early intervention services from all other special education services. The main problem is that what makes Part H so effective —positive collaboration between families and professionals— is lost once the child enters the school system. Too often, when young children transition from Part H services to those administered by local

education agencies, the needs of the family unit are no longer considered and the focus of services switches solely to the child. This change is not gradual: It happens literally overnight for families. The sudden shift to a less family-centered education can be quite traumatic for families and children.

One witness offered a solution to this problem:

Offer possibilities such as service coordination (case management) beyond age 3 perhaps as a specified related service option in Part B so as to facilitate easier access and entry to services. (Pascal L. Trohanis, Charlotte, NC)

Part H's core values and philosophy must be transitioned along with the student into early education and beyond. Suddenly throwing a student into a new educational setting can erase the benefits and gains made by the family and child during the Part H program. Parents testifying at the hearings were adamant in their belief that they should remain as integral parts of their child's education once they leave the "safety net" of Part H. If this were the case, parent dissatisfaction with the IEP process and other aspects of special education (see the chapter on "Parent Participation and Shared Decision Making") might be significantly reduced.

The next change requiring an effective transition occurs when students enter middle school or high school. Entering middle school is difficult for almost any student, but can be even more so for students with special needs. This transition is difficult for many reasons. Students are leaving settings where they had just spent six or seven years. All of a sudden, they are required to change rooms between each class during a limited time period. Students also move from the familiarity of having the same teacher

for the entire day, and this lack of familiarity affects teachers' abilities to provide proper instruction. Students also lose the security of having the same classmates they had in elementary school. Socially, they must adjust to an environment that is far more demanding and less predictable than elementary school. Most parents whose children had reached at least middle school had experienced frustration from this sudden change in educational settings.

The transition from middle school to high school is also very important. Not only do students enter a new school, but it is in high school that IDEA's mandatory transition services must be initiated. Parents consistently stated that in spite of any past academic problems, a successful career in high school can determine their child's later success in life. Again, the change to a new school can reverse positive results gained through earlier educational experiences, if the supports that ensure benefits are not transitioned along with students.

Changes Need to Be Made in the Process of Transition Planning

Annual IEPs Need to Reflect the ITP and the Overall Vision for the Student

The student needs to be empowered. Too many people are making too many decisions for that student with the disability without letting them in on the process. (Fred Greasby, Milwaukee, WI)

At best, it seems ITPs are one-page documents completed to primarily meet a legal requirement. Useful ITPs developed with the essential people involved happen rarely. The transition planning requirements of IDEA need to be strengthened and schools need to be held accountable for helping students

move successfully from school to what lies beyond. (Carol Gonsalves, Berkeley, CA)

The entire plan was driven by the vision he had and that we had, not by existing programs in the school district. The staffing team worked together creatively over several months. The interests, strengths, and abilities of the student were used as building blocks in developing...goals and objectives. (Judy Martz, Denver, CO)

Families testified that the only IEPs or ITPs they found satisfactory were those in which they were actively involved and had an ongoing role in monitoring. The general consensus was that otherwise, the IEP process was not effective for transition planning. There are a number of reasons why this is so.

First, the IEP provides annual goals and objectives for each student to work toward during a school year. This means that the IEP does not necessarily follow a family's and student's postschool vision, hopes, and preferences. Accordingly, the IEP is not designed *per se* to support the intended results established in the ITP process. However, the IEP can augment the ITP process, as exemplified by a family in Colorado Springs, Colorado. This family wanted their son with a developmental disability to graduate from high school at age 18 with the rest of his peers. They also wanted him to receive transition services and an IEP from the school, but not to receive ongoing supports in the school setting, believing that the more appropriate setting was that of a college campus, the same setting many of his high school peers were entering. The school provided services, coordinating with the college and adult service agencies in order to facilitate the change of educational setting for this young man.

Second, parents spoke about their frustrations with school personnel and teachers—in both general and special education—who refused to implement the IEP and who, in some cases, even refused to look at the IEP. At times, the IEP goals were changed or never implemented without the consent or knowledge of the family. So, even if a good, meaningful plan was written and followed the vision for the student, its lack of implementation blocked anticipated results, caused it not to meet the purpose intended, or indicated that the process had been completed simply to satisfy an IDEA requirement.

Third, there may be little or no continuity from year to year and IEP to IEP. The only individuals who monitor continuity are parents and sometimes an effective educator or school employee. Without some continuity between school years, grade levels, and school buildings, the ITP and future planning process is meaningless. The lack of continuity from education plan to education plan and between annual education plan and transition plan causes students to be tossed about the educational setting and does not help them see the relevance between school goals and life goals. If foundations are not laid and built upon, then it is doubtful that the desired adult results can be achieved.

Finally, schools need to provide follow-up and follow-along services for the students who have transitioned out of the school and into the community. These

services would require the schools to be more proactive and to provide more comprehensive transition planning and IEPs to achieve the intended ITP results.

The Social Aspects of Transition Need to Be Emphasized

Community based instruction needs to be expanded so that students are really prepared for adult life, giving them opportunities to be fully included in society at an early age so that when it is time for them to enter the adult world, they are totally prepared and comfortable with themselves and their environment in which they will live and work. (Maureen Devaney, Philadelphia, PA)

It is important and necessary that people be allowed to mix with others. People learn maturity mostly by being with their peer groups....When I was with the group of teenagers that took me under their wings, I felt like I could do anything. (Bill Rush, Des Moines, IA)

People with disabilities, transitioning out of school, learn all the skills necessary, but they do not know how to socialize, for they focus more on job skills more than they do socialization, which begins at school at the locker rooms, pep rallies, and others. (Debbie Allen, Denver, CO)

In order for students to have a truly successful transition from school to postschool life, they must have social experiences and skills in school that they can transfer to their lives after and outside of school. Witnesses repeatedly emphasized that social experiences and skills are often more important than vocational or academic skills. Too many individuals with disabilities who have transitioned out of school programs lack meaningful friendships. They are isolated, bored, depressed, and without any sense of a social life.

Witnesses offered many suggestions on how to overcome this problem. First, the supported inclusion of children with disabilities in regular neighborhood schools can greatly facilitate the transition from school to adult life. Students learn social skills, succeed in school, and transition successfully as adults when they have ongoing social connections with their peer groups. This includes participation in the same activities as their peers as a valued member of the peer group, not as a person needing to gain a skill. True success for students with disabilities happens in an inclusive setting with the appropriate supports and facilitators. Inclusion was cited as the number one factor in making successful transitions by those who described successful transition experiences.

Second, school personnel, families, and friends must work together to establish and facilitate friendships and connections with peers long before the transition age of 16. These relationships need to be fostered beginning in elementary school and should continue beyond graduation from high school. Involving peers and friends in the process of transition planning and assisting the student with a disability to succeed in more than one realm promotes continuity between educational and social settings.

Third, self-advocacy skills are important for students with disabilities in order that they are able to communicate the accommodations and modifications they may need in social and community settings. All students, regardless of disability, need to learn this, not only through direct instruction, but also in their dealings with friends, associates, and peers on a daily basis. This type of instruction and experience needs to

be provided to students with disabilities so that they can make successful transitions and be more independent in their lives after school.

Collaboration is Vital to a Successful Transition Process

Language requiring service coordination should be strengthened. There is a need for a strong integrated system of service delivery and transition teams that begin working together in the early planning stages of the student's transition process. (Kelly Davis, Albuquerque, NM)

Adult services need to be accessed before a student exits school to ensure smooth transition. Overlap of responsibility between education and adult service providers is necessary....A period of shared responsibility is needed to facilitate successful transition. (Meredith Post Gramlich, Berkeley, CA)

[We need] stronger interagency programs so that we break down the separation between the educational system, the medical system, DVR, DB...These programs [need to] become interlinked in order to provide a network of support for all of our citizens within our nation. (Robyn Rehmann, Anchorage, AK)

Collaboration was a recurrent theme throughout the hearings. All participants who mentioned collaboration were in favor of strengthening IDEA's collaboration requirements and testified that teamwork creates success in school and in the transition process. Thus, Interagency Coordinating Councils, like those developed under Part H, should be developed to ensure and facilitate collaboration among individuals involved with transition.

More than interagency collaboration is required. Collaboration needs to involve students as well as parents. Yet the lack of a family-centered focus on the part of many schools impedes collaboration. For example, one mother mentioned that the school

would not allow her to attend school-sponsored training that would provide her with the skills she needed to help her son at home. Without exception, collaboration with families is key to a student's success in school, especially during a period of transition.

Community members and personnel from service agencies also emphasized the schools' lack of collaboration. Witnesses stated that often community service agencies such as Centers for Independent Living are willing and eager to work with students, families, and schools in transitioning from school to adult life, but the narrow focus of the schools on matters directly relating to their specific areas of responsibility impairs effective collaboration. One service provider strongly recommended that service agencies and the schools should enter into agreements to ensure collaboration. In order for community agencies to conduct long-range planning to provide services when students need them, the agencies must first know what these students need. To reduce their waiting lists and develop person-centered service models, service agencies need to have time to plan and coordinate services before a student graduates from high school.

As mentioned earlier, more families and students are considering postsecondary education as an option. This requires collaboration among schools, community agencies, and postsecondary programs. In order to make postsecondary education a viable option for increased numbers of students with disabilities, personnel and students at postsecondary schools need to be brought into the transition process.

Finally, collaboration needs to occur within schools and school districts. The continued huge chasm between general education and special education results in a lack of opportunity and success for all students. Training for all future teachers should promote collaboration. Indeed, changing the structure of education at the university level could contribute to an overall improvement in collaborative efforts among educators. By uniting special and regular education and by training teachers to teach *all* students and to collaborate toward that end, schools will be more effective overall. However, such restructuring is a two-way street, and the schools, on a building and district basis, must also reform themselves to meet the changing status of students today. This means the school atmosphere must be conducive to collaboration. Teachers need to use each others' strengths and knowledge to achieve one common goal: educating all students to their maximum potential by collaborating with each other, families, and the community.

Recommendations: Transition

In order to improve the transition of students receiving special education from school to adult life, the Federal government should implement the following recommendations:

1. Lower the mandatory age for the initiation of transitional planning from 16 years old to 14 years old.
2. Encourage State and local education agencies to strengthen community-based training and work experiences, inclusive social skills experiences, independent living experiences, and self-advocacy training for students with disabilities in secondary school programs.

3. Require that a member of the transition planning team or that a person appointed by the transition planning team serve as a coordinator for services to be provided under the ITP, integrating these services with those in the IEP.
4. Encourage State and local education agencies to be flexible in the design and implementation of services to students with disabilities between the ages of 14 to 21, particularly with regard to the provision of IEP-related services and supports outside of the secondary school campus.
5. The Department of Education should explore the feasibility of continuing the family-based focus of services delivered under Part H to students and families receiving services under Part B of IDEA. Service coordination (case management) should be available as a related service to students and families throughout the transition from Part H to Part B services.

DISCRETIONARY PROGRAMS

Statement of Law

Although Part B of IDEA, which creates substantive and procedural rights for students with disabilities and their families, was the major focus of the testimony, it was by no means the only focus. IDEA also authorizes other very important programs. Overall, these programs greatly enhance our national capacity to improve special education. They do so through Subchapter III (which authorizes programs and projects such as regional resource centers, services for deaf-blind students, early education, services for students with severe disabilities, postsecondary education and transition services, and programs for students with severe emotional disturbance); Subchapter IV (personnel preparation); Subchapter V (research); Subchapter VI (instructional media); Subchapter VII (technology and educational media and materials); and Subchapter VIII (early intervention for infants and toddlers, also called Part H).

These programs complement Part B in several respects. First, Part B authorizes aid to States to educate all children with disabilities, including those in early education (ages 3 to 5), those who have been categorized as having severe and multiple disabilities or severe emotional disturbance, those who are eligible to receive transition services as part of their IEPs, and those who are eligible to receive assistive technology services and devices as part of their IEPs (20 U.S.C. Secs. 1401, 1411, 1412, and 1413). In addition, Part B requires States to create a comprehensive system of personnel development (20 U.S.C. Sec. 1413(a)(3)). This system should ensure an adequate supply of qualified

teachers and related services personnel, establish standards for training those personnel, create a system of continuing education for them, and establish procedures for disseminating significant knowledge and adopting promising practices.

Overall Impact on Programs

There can be little doubt that the discretionary programs and complementary Part B provisions have been quite useful to date in improving the overall delivery of special education and related services. However, there are several areas where their implementation could be improved. These areas will be discussed below.

Personnel Development

Witnesses, the majority of whom were parents, offered opinions and insights on personnel development at least five times more often than they did on parent training programs.

The only specific negative I have seen in the Albuquerque Public Schools is that even when a teacher is provided who is experienced and trained and educated in special education, the rest of the professional staff may not have any information, any education....The school system has an obligation to run a large system. You can't drop everything for my child or anyone else's. I felt some problems that we ran into could have been avoided if the faculty who were dealing with [my son] in these situations were even told....I'm not expecting every teacher to be trained in special education, but I thought that the schools could alert all of the teachers as to what kind of programs exist at the schools and what kind of students were attending these programs.
(Congressman Steve Schiff, Albuquerque, NM)

Witnesses offered varied views on the adequacy of personnel development programs, telling personal stories of how IDEA and its teacher in-service and preservice provisions affect students' education. Parents especially voiced concern that teachers in both regular and special education were inadequately prepared for actually teaching students with disabilities. Reasons for this inadequate preparation were offered by parents and other witnesses, ranging from a lack of college preparation and coursework to a lack of concern.

We acknowledge, we understand, and we're terribly concerned about many of the problems that are related to the quality and quantity of [the] special education and related services work force. But in our professional opinion, these problems would be much worse without a strong Federal role and commitment....There is a current and continuing shortage of special education university faculty. Simply put, there [are] not enough doctoral graduates whose career choice is higher education to fill current and projected vacancies. This shortage will —and is— affecting the supply of new teachers, related services personnel, and the in-service capabilities to produce people who are capable to provide inclusionary programs in the public schools.

Federal dollars must be maintained and increased to support individuals pursuing doctoral degrees, specifically interested in becoming university faculty. We are concerned about the ability to generate new knowledge, new curriculum materials, new approaches, and to verify those through research, for just as there is a shortage of new people, new leaders, and faculty, there is a shortage of people who are researchers. (Deborah Doherty Smith, Albuquerque, NM)

The most frequent areas of concern or complaint regarding personnel preparation were as follows: the ability of teachers to provide effective instruction on a daily basis in classrooms, certification requirements, administration, and education in the least restrictive environment.

Witnesses who expressed concerns about the day-to-day ability of teachers to function effectively in classrooms made the following suggestions to improve teacher training:

- ◆ Teachers need sufficient training in specific areas of special education.
- ◆ Teachers need more in-service and preservice training, and such training needs to be required rather than merely suggested.
- ◆ Teachers need training on how disabilities can affect student behavior.
- ◆ Teacher training on collaboration needs to move beyond "token" collaboration, beyond merely putting in an appearance at IEP meetings and other conferences.
- ◆ Classrooms need more teacher aides or paraprofessionals.

What I would like to see in language in the reauthorization is to encourage university programs that are preparing our personnel to look at preparing teachers —quality teachers— who are capable, willing, [and] committed to educating all children, regardless of their diverse cultural backgrounds, regardless of their diverse learning needs, regardless of their talents, regardless of the obstacles and talents that they bring to the classroom.
(Diane Ryan, Philadelphia, PA)

[There is a] shortage of personnel to teach blind children and the university programs are limited [in] number. We rely very heavily on Federal dollars for their continued existence. This is an appropriate use of Federal money.
(Lynne Koral, Anchorage, AK)

With the shortage of early intervention specialists and recruitment issues...[I was] wondering if...there could be some language in there that could serve to recruit people into the fields by being able to say, "If you come into the field and you do your education and you go out and serve...especially in Alaska, you would have your loan deferred, or part of it." (Susan Jones, Anchorage, AK)

On the subject of teacher certification, witnesses made the following suggestions:

- ◆ All student teaching needs to require work in a setting that has students with disabilities.
- ◆ Teachers need more frequent recertification.

In discussing administrative concerns, witnesses recommended the following:

- ◆ School counselors need training for working with students who have disabilities.
- ◆ School districts need to recruit more qualified teachers. At present, administrators are allowing teachers who are not qualified to teach special education to do so.
- ◆ Schools and school districts need a full range of services, and they need to encourage teachers to work with, not against, parents and advocates.

We need to make sure that the administrators and the principals are included in the team and are educated and foster a positive outlook and attitude, one that breeds...confidence [into] teachers, letting them know that we can try to be as innovative as possible. (David Berube, Anchorage, AK)

Witnesses' concerns regarding the least restrictive environment centered on the need for teachers in regular education to receive sufficient preparation to integrate students with disabilities. Many universities continue to train teachers in regular education separately from special education and to endorse segregated settings for students with disabilities. Witnesses urged school and university personnel to update their attitudes to better integrate students with disabilities:

Services for many children include regular classroom situations. Regular teachers lack adequate preparation to implement programs and to teach and/or modify curriculum for students with special needs. Teachers do not

receive adequate preservice training and little or no in-service training.
(Linda Speich, Charlotte, NC)

The element that seems to be missing in all this is the university's part in preparing teachers. They continue to have a separate track teaching regular education teachers over here and special education teachers over there. We're not preparing teachers properly. (David Maltman, Anchorage, AK)

At the college that I go to...the instructors there are teaching us a different perspective of IDEA than what I am hearing here. They teach that including students with disabilities is against the LRE requirement and that segregated classes and schools are the best environments for students with moderate or severe disabilities. They teach that children will be dumped without support. My sister, who is a regular education student, has been told that she will be required to change catheters if inclusion gets through. I personally heard that there will be students in hospital beds in my algebra class that I'm teaching. If we're going to make a difference, we need to start with higher education. Attitudes need to be changed. Right now, many schools reflect an attitude that's back in the 50s. We need to get to the 90s. I'm calling for the education of educators. (Patty Gilg, Des Moines, IA)

In many school districts in Pennsylvania, teachers are trained in teaching practices that hinder inclusive education, such as teaching as talking, reliance solely on textbooks for instructional material, and referring students to special education programs first and adapting instruction as a last resort. Reform of teacher training can have a significant impact on teachers' classroom practice, and enhance the ability of regular education to be used to adapt instruction to the needs of all students. Yet if change in teaching practices is not supported in the schools, [then] it dies as teachers return to the norms of instruction that are currently enforced in original training. (Judy Gran, Philadelphia, PA)

I know from first-hand experience that our teacher preparation programs are failing to provide this type of background to the vast majority of students. General education majors are entering the teaching field without the most basic understanding of how to modify curriculum and instruction to meet the needs of a wide range of students. Special education majors are being prepared to teach primarily in segregated settings and have little awareness of the role of consultant/support teacher and how to apply their specialized knowledge about disabilities in the context of a general education curriculum. (Linda Rambler, Boston, MA)

Some individuals discussed areas where they perceived a need for an increased number of personnel with specific skills: qualified sign language interpreters; personnel with skills in teaching students who are blind or visually impaired, deaf or hearing impaired, autistic, and those with attention deficit disorder; and personnel with expertise in assistive technology, mediation, the learning styles of minorities, biopsychology, physical therapy, and occupational therapy.

Although the majority of consumers spoke of problems created by lack of teacher, school, or school district compliance with IDEA, the following recommendations were offered in order to address these problems. All suggestions were directed toward improving teacher training. However, these recommendations involve overall education reform as well as specific strategies for individual schools and districts.

Resource suggestions included the following:

- ◆ Create a resource hotline or on-call information center for teachers.
- ◆ Supply paraprofessionals to assist beginning teachers.
- ◆ Use students and adults with disabilities and their parents or advocates as resources for teacher preparation and in-service programs.

Witnesses made two recommendations to improve the quality of teaching:

- ◆ Teachers should receive positive reinforcement for working with students with disabilities.
- ◆ Training should be mandatory for school boards, administrators, and any persons connected with students with disabilities, not just for teachers.

Other consumer recommendations concerning ways in which IDEA implementation might be improved in the area of personnel preparation included the following:

- ◆ Advocates should inform teachers of latest advancements.
- ◆ States should share successful programs.
- ◆ The IEP should include a statement of training needed by teachers in order to implement the IEP.
- ◆ Teachers need time off for staff development and training.
- ◆ Goals 2000 should unite special education and regular education reforms.
- ◆ Teachers need incentives to gain appropriate training.
- ◆ Special and regular education certification should be merged, and
- ◆ Grant money should be supplied directly to local districts for teacher training programs.

Parent-As-Collaborator

Witnesses also testified about the parent-as-collaborator and the Parent Training and Information (PTI) Centers. While testimony clearly indicated solid support for the PTIs, witnesses indicated that the performance of PTIs would be improved with additional resources. They universally testified that increased funding would improve the PTI's effectiveness.

With the help of the parent training and information center in Montana, we were able to make our case and use special education process successfully. (DuWyne Geist, Denver, CO)

The information on what's out there needs to be found and made available to parents, either through a parent information center or through the Part H efforts, but it can't be left up to the schools in the kind of elusive situation that it is now. (Kathy Thomas, Denver, CO)

What parents need is training and education, mandated training and education. I envision a system that every parent, when they have a child entering school, be given an information packet, including IDEA, 504, ADA and...the State regulations. Along with that information package, I envision a list of advocate and parent support systems so they can learn how to use those systems. (Cindy Sirois, Boston, MA)

I feel it is vital that PTI be expanded to fully meet the needs of children with disabilities and their families. The need for parent training and information has grown dramatically in the last five years. Sadly, PTI funding has grown minimally. PTI has made families' involvement a reality. (Laurie Collins, Charlotte, NC)

Recommendations: Discretionary Programs

In order to improve the ability of discretionary programs funded under IDEA to meet the needs of the field of special education more effectively, the Federal government should implement the following recommendations:

1. State clearly that the purpose of teacher training programs funded under personnel preparation grants is to produce teachers who are highly skilled in providing intensive developmental and remedial instruction to students with disabilities in order to support their participation in the least restrictive environment.
2. Allocate resources to continuing education programs for currently employed special education teachers in order to allow them access to new information and instructional strategies that will enhance their ability to provide high-quality services to students with disabilities.

3. Require that all students preparing to be special education teachers have ongoing practicum experiences in typical neighborhood schools that educate children with and without disabilities in the same age range as children they are preparing to teach.
4. Expand diversity among special education professionals through continuing to target funds to minority institutions for the purpose of recruiting and preparing minority college students to enter the special education field. Moreover, institutions of higher learning in which 25% of the student body is a part of a minority population should be considered minority institutions which qualify for these funds.
5. Continue support for the preparation of teachers with the technical skills required to teach children with sensory impairments and low incidence disabilities and for the training of doctoral students with successful experience in teaching who are committed to training special education teachers upon graduation.
6. Create financial incentives to attract teachers of students with sensory disabilities and low incidence disabilities as well as teacher trainers, through student loan cancellation programs tied to actual work in these areas over a number of years.
7. Create preference in the award of personnel preparation grants to colleges and universities that provide students training in the field of special education with experience in typical education courses and environments that integrate students with disabilities and typical students.
8. Increase funding for the Parent Training and Information centers in order to ensure that all parents —particularly those in minority and rural communities— receive information and support as they become active collaborators in the education of their children.
9. Applicants for funds under the personnel preparation program should be required to describe in their grant applications how they will involve local Parent Training and Information programs in their personnel preparation efforts.

FUNDING

Congress originally intended to contribute 40 percent of the average cost of educating children with disabilities beginning in 1982...Last year the Federal government provided only 7 percent of the cost. (Congressman Cass Ballenger, Charlotte, NC)

The problem is every day that a child goes without services, that school district saves money. (Edris Klucher, Albuquerque, NM)

Statement of Law

Funding is an essential part of IDEA. In 1975, when Congress found that it was necessary to assure the constitutional rights of students with disabilities and, to that end, to help the States educate all students with disabilities, it authorized several appropriations for special education. It is important to note that one reason Congress passed the original Education for All Handicapped Act was to assist States in meeting their obligations to provide equal protection under the law to students with disabilities. This obligation had been affirmed in several court decisions prior to the passage of the Act, and the Federal response represented an effort to provide financial and other assistance to State and local governments which would otherwise be totally liable for expenses associated with providing a free and appropriate public education to students with disabilities. As such, Federal funds were intended to supplement, not supplant, State and local funds to achieve this end.

Under IDEA, the appropriation that aids students' education most directly is in Subchapter I, the basic grant to States to fund State and local education agencies in

providing special education and related services. In 1975, Congress authorized appropriations at the maximum level of 40% of the excess costs of special education by 1982. However, Congress has never appropriated that amount. As of fiscal year 1995, Congress has only appropriated a maximum of approximately 8 percent of the excess costs related to special education.

The appropriations allocated to States are based on the number of students identified as requiring special education in each State. A State receives Federal funds if the U.S. Department of Education approves the State's application for funding. The Department must approve the application if the State assures the Department that it will comply with Part B of IDEA. A State may retain a maximum of 25 percent of the Federal allocation and must pass the remainder of the Federal allocation to its local education agencies, based on the number of students receiving special education in those LEAs (20 U.S.C. Secs. 1411, 1412, 1413, and 1414).

Other appropriations that assist the States are contained in other Subchapters of IDEA:

- ◆ Subchapter III authorizes regional resource centers, aid for deaf-blind students, early education, programs for students with severe disabilities, postsecondary education and transition services, and programs for students with severe emotional disturbance.
- ◆ Subchapter IV funds personnel preparation.
- ◆ Subchapter V funds special education research.
- ◆ Subchapter VI funds instructional media.

- ◆ Subchapter VII funds technology and educational media and materials.
- ◆ Subchapter VIII creates and funds early intervention for infants and toddlers.

The Need for Adequate Funding

An ever-present concern of consumers throughout the hearings was the need for more adequate funding for IDEA:

I can't believe after...20 years that they would ever consider not reauthorizing [IDEA]. It would also be nice were it to be completely funded. I am speaking not as a funding expert, not as a lawyer, not as a teacher, but as a parent. Because even after four years of sitting on a citizen advisory committee, I still find the language, the funding formulas for special education described in this Act to be completely off-putting. (Lindsay Merryman, Berkeley, CA)

Witnesses expressed overwhelming sentiments of disapproval with the lack of guidelines in providing and allocating funds:

In many States, because special education dollars are tied to programs, not to students, there are no financial incentives to develop uniquely tailored programs that support students with special needs in the classrooms. These factors mitigate against the likelihood that the student will be educated in the least restrictive environment. (Amy Goldman, Philadelphia, PA)

They were also discouraged by the seeming lack of adherence to Federal mandates and the lack of effective remedies available to them:

We're fined for late payments, speeding, disturbing the peace and dogs running loose. Surely a child's education is important enough to warrant at least equal attention. (Judy Bonnell, Albuquerque, NM)

A receivership option, rather than the withdrawal of funds, should be considered for districts that refuse to comply with the LRE mandate. Fiscal incentives for segregated catastrophic placements and fiscal disincentives to placing students with challenging needs in regular school settings must be

removed and replaced with a child-centered funding mechanism that enables maximum flexibility for supporting each child in natural classroom environments. (Linda Rambler, Boston, MA)

IDEA is often regarded as the maximum requirement by many school districts, when it was intended to be the minimum. (Bonnie Dunham & Lori Salvi, Boston, MA)

The general consensus was that students with disabilities —those for whom the program was created— are the ones who are suffering the most from the lack of adequate funding and enforcement. The government must make progress toward guaranteeing full funding of IDEA, issuing specific guidelines for the use of funds to support basic requirements of IDEA, such as placement in the least restrictive environment.

Funding has not gone up significantly since Public Law 94-142 was first passed. Now we have teachers' salaries that have increased, we have assistive technology to purchase, we have adaptive physical education equipment to purchase, and we have more need for PT, OT, and Speech. (Isabelle Mims, Charlotte, NC)

I often hear about money and the shortage of money, but I don't think money is the only answer. I really don't. I have seen people do wonders. When we went to school, for some reason, we didn't have all these wonderful resources available. I'm not saying we should go back to that, but neither should I suggest that we always hear that money is the only answer for serving children with disabilities, or money is the only obstacle that we have to overcome, because I think there are other issues involved. (Rafaelita Bachicha, Albuquerque, NM)

General Funding Advice from Witnesses

If the categorization and IQ testing could be ended and funding sent through the IEP so that various points on the IEP could be charge items, then the emphasis and our funding shifts from funding the disability to funding the education, which really makes more sense. (Corinne Quadland, Milwaukee, WI)

I would encourage this Council to examine ways to spread the money out from district to district more based on the specific needs of that district and the specific needs of the students. (Dave Calvert, Charlotte, NC)

Most witnesses agreed with the general sentiment that Federal funds should be increased to the 40 percent of excess cost as specified in the law. Other witnesses called for changes in the manner in which funds are allocated. Examples of suggested changes in this area would include allocating funds based on a presumed incidence model rather than on the current child count. Witnesses expressed concern that the current system encourages school districts to label children in order to receive increased funding. Under a presumed incidence model, funds would be allocated on the basis of the expected percentage of students with disabilities in the States. Adoption of a presumed incidence model might cut back on the significant degree of effort and paperwork that currently occurs under the child count requirement. More importantly, it would remove the current incentive to label children for the purposes of increasing funding. Such a model might be weighted to allow for various demographic variables (such as high rates of poverty) that are associated with higher levels of disability, as are other government funding programs.

Witnesses also suggested that other funding sources might be explored. For example, some related services provided under special education are reimbursable under Medicaid. Interagency funding agreements between State agencies can be developed to indicate clearly which agency is responsible for funding certain services. However, another concern of consumers was that funding be provided with a minimum of

bureaucracy. While it is necessary for administrators to work out the intricacies of funding arrangements, consumers need to experience continuity and predictability. From the consumer perspective, funding should follow a student throughout his or her education. As customers, people do not expect to hear about the cost of every part in an automobile they are purchasing. As customers, parents of children receiving special education should not have to listen to an annual debate on how —or whether— their children's education will be funded.

Reducing Financial Barriers to Placements in Less Restrictive Settings¹⁴

Many witnesses were concerned with the failure of school districts to implement the principle of the least restrictive environment effectively. These witnesses pointed out how reducing current financial barriers to less restrictive placements could result in better implementation of this requirement.

There must be financial incentives for schools that follow IDEA in first placing children into typical classrooms with appropriate aids and supports...Funding should be allocated to enable successful inclusion teams to teach others how to achieve inclusion. (Kathie Snow, Denver, CO)

There also appears to be inadequate funding for inclusion, or at least that is what the districts keep saying. We keep hearing statements, such as, "Yes, the Federal government mandates placement in the least restrictive environment, but no monies have been forthcoming from either the Federal or State governments to implement inclusive education." There are simply not enough inclusion programs available. There is tremendous inflexibility in the system. (Karen Robard, New York, NY)

¹⁴ See National Council on Disability (1994). *Inclusionary education for students with disabilities: Keeping the promise*. Washington, DC: Author.

The number of related services that these kids require should help to determine their funding level as opposed to this self-contained versus resource versus regular classroom placement. The way that it's set up—in this State anyway—it's sort of a deterrent to an inclusion model. Districts get more money to self-containing these kids and there's something not right about that system. (Margaret Mochak, Anchorage, AK)

Beyond the mere reduction of barriers, witnesses suggested that there should be financial incentives for schools that implement IDEA properly in placing children in typical classrooms. Beyond providing flexible, child-centered funding to support inclusionary placements, funds could also be allocated to train parents and professionals in the practical aspects of supporting students with disabilities in less restrictive placements. Such training could utilize the expertise of parents and professionals who had worked together to bring about successful inclusionary programs for students with disabilities. In this way, local knowledge concerning what works best for students in inclusive placements could be used to expand opportunities for increased inclusionary placements.

While many parents complained that they had been told that there was "no money" for inclusionary programs for their children, our research indicates that the real problem is not that there is "no money"; it is that available funds are tied to segregating programs and practices. In truth, the financial cost of segregation is enormous. While it is not the case that special education costs would go away if students were served in typical schools, the billions of dollars that are spent every year to maintain segregated schools and to provide segregated transportation services for students with disabilities

could be used to significantly improve educational achievements in integrated schools. At a minimum, the Federal government should remove current regulatory provisions and practices under IDEA which essentially encourage and reward the segregation of students with disabilities. Proactively, the Federal government can take steps to reward compliance with the law and creative approaches to ensuring that students with disabilities have every opportunity to participate in the lives of their local schools and communities.

Recommendations: Funding

In order to address the many concerns and suggestions made by consumers during the hearings, the Federal government should implement the following recommendations:

1. Allocate Federal funds that support the education of children with special needs to the States based on a weighted presumed incidence model, with allowance for factors such as high numbers of families living in poverty, difficulty of personnel recruitment in rural areas, etc.
2. Increase overall Federal funding for IDEA. Base increases in grants to individual States on the weighted presumed incidence model described above *and* on progress in achieving results such as the following:
 - a. Higher graduation rates for students receiving special education;
 - b. Steady increases in the numbers of students receiving special education in regular classrooms within typical neighborhood school buildings;
 - c. Higher rates of inclusion of students receiving special education in typical student assessment protocols designed to measure overall school district or State performance;
 - d. Higher rates of employment as adults for former students who received special education.

All States might be granted a proportional share of the increase during the first three years of funding, with a "special education superfund" beginning in the fourth year to reward those States which have invested the initial funding increase in order to produce better results as described above.

3. Unlike the present situation in which many States essentially reward local education agencies for placing students with special needs in more restrictive settings, require States and local education agencies to adopt and implement "placement neutral" funding practices, wherein at least the same amount of funding is available to support a student receiving special education in a typical school environment as has historically been allocated to place that student in a segregated environment.

4. The Department of Education should consider combining many of its discrete funding authorities into a smaller number of functionally-based programs in order to streamline operations and make funding authorities less confusing to consumers.

SPECIAL EDUCATION AND THE GOALS 2000: EDUCATE AMERICA ACT

Statement of Law

In 1994, Congress enacted P.L. 103-227, the Goals 2000: Educate America Act. In that law, Congress recognized that the Governors, State and local education agencies, and concerned parents and other citizens, particularly leaders of the business community, have been engaged in a sustained effort to reform America's schools. This contemporary school reform movement was launched in 1983 by the publication of *A Nation At Risk*, a report on the state of education authorized by then-Secretary of Education Terrell Bell. The school reform movement also received powerful support from the National Governor's Association with its publication in 1986 of *A Time for Results*. The Goals 2000: Educate America Act represents the Federal government's response to the call for basic school reform.

Among other provisions, the Act helps States to develop standards for assessing all students (including students with disabilities), setting goals for local education agencies, and evaluating how well these agencies and students meet those goals (P.L. 103-227, Secs. 220(a)(2) and (c)(1)(c) and 241(d)). The Act and its accompanying Congressional Committee Report also make it clear that parents and family members of students with disabilities should be involved in setting the assessment standards and school goals. Moreover, the Act requires the National Academy of Sciences to study the ways in which special education consumers —such as parents, family members, and

students— are involved in school reform activities (P.L. 103-227, Sec. 1015). Likewise, the Act and Committee Report acknowledge that school reform creates extraordinary opportunities for State and local education agencies to implement the principle of least restrictive environment and to include students with disabilities in regular education programs to a far greater degree than they have in the past. Finally, the Act recommends that Congress should fully fund IDEA (up to the authorized maximum of 40 percent of the excess cost of special education) by reallocating funds from the non-educational areas of the federal budget (P.L. 103-227, Sec. 1012). Clearly, then, Goals 2000 presents an unusual opportunity for special education consumers to influence the whole field of education.

Testimony Concerning Goals 2000

Although there were not many witnesses who testified about Goals 2000, those who did made several points. The first of these points is that Goals 2000 challenges various practices that have evolved during the implementation of IDEA, representing a new opportunity for students with disabilities to be provided with greater access to schooling as well as increased access to more settings within a school.

I'm concerned that at some point, innovative States might start bumping their heads against a ceiling of IDEA compliance and check-offs...and not be able to enact the kinds of reform that will move students with disabilities forward. There are still States and local districts that need the Federal mandate to ensure access right now. But we also need to be forward-looking, at where States are headed five and ten years from now. And as trust grows between parents and schools, as proven practices in serving students are established, and as classrooms become more adaptive and open to serving a diverse set of students, we need to open new ways of doing business with States and local districts. (Congressman Cass Ballenger, Charlotte, NC)

The second point made by witnesses was that school reform and IDEA are concerned with the same issue, namely, the effective education of all students, including students with disabilities:

The National Council on Independent Living believes that special educators must be included in the plans to teach the basic skills detailed in the...Goals 2000 Act. (Paul Spooner, Boston, MA)

Goals 2000 has significant language about how children with disabilities are going to be included in the education reform. Goals 2000 has got to be related in some way to IDEA. And we have to develop a system [where] we don't look at compliance as only dotting the "i's" and crossing the "t's," but we look at compliance as having hard and fast beneficial educational outcomes for every student, whether that student is a college prep student or whether that student is a student with severe and profound mental retardation [learning] self-help skills. (Connie Hawkins, Charlotte, NC)

However, one witness did caution that fundamental features of IDEA, such as the requirement for IEPs, should be continued as school reform takes effect:

The individual education program designed specifically for each child with a disability by a team of parents and professionals must take precedence over any local or State educational guidelines which are developed to reform regular education. (Mary Ellis, Charlotte, NC, p. 134)

The third major point made by witnesses concerning the impact of Goals 2000 on IDEA was that school reform does indeed create possibilities for implementing the least restrictive environment requirement to a greater degree, potentially allowing special education students to enter regular education to a much greater extent than in the past. Lee Schulz, Executive Director of the Southeastern Wisconsin Center for Independent Living in Milwaukee, made the point that special education has created a cadre of professionals whose purpose is to serve children with disabilities; but the downside of

the creation of this cadre is that teacher preparation programs have separated regular and special education programs. This separation has effectively limited the nation's teachers in their abilities to educate students with disabilities.

Joyce Marshall of Knoxville, Tennessee, addressed the opportunities to increase the inclusion of students with special needs in regular education under Goals 2000 in these words:

There have been basic concerns about whether Goals 2000 would include children with disabilities and how this would work. The United States Department of Education's sponsored research should show how this should work...For over a decade the Department of Education and various State and local education authorities have provided millions of dollars and countless human hours in supporting model demonstration projects in the area of inclusive education all across the country. (Joyce Marshall, Charlotte, NC)

If special education is to be properly integrated into school reform efforts, it must be redefined as a support to all students, families, and school district staff. At present, special education is viewed in many parts of this country as a place where students who are considered "different" can be "placed." It is thought that this place needs to be staffed only by "experts" who need to be grouped together in much the same manner as the staff of a hospital emergency room. This model of special education has contributed to the continued segregation of students with disabilities, countless violations of both the letter and intent of the least restrictive environment provisions of IDEA, and the withholding of the many potential contributions special educators could make on a daily basis in schools across America if they were seen as experts in individualizing instruction for all students requiring assistance, not only those who are labeled.

As an alternative, special education could be redefined as a *support system* located in every school in America for all students. Under this model, *all* educators might be able to work together to, in fact, support *all* children and youth. This model would not be directed at "special education" *per se*, but would rather be directed at the needs of all students, whatever their support needs. This model would address the needs of bilingual or bicultural students, gifted students, and others, as well as the needs of educators and families. It could well result in America having the best community school-based student support systems in the world, by ensuring that maximum achievement is attained by all students regardless of gender, race, disability status, cultural or linguistic background, or other individual characteristics.

Recommendations: Special Education and the Goals 2000: Educate America Act

In order to ensure that students receiving special education are fully and effectively included in Goals 2000 and other education reform efforts, the Federal government should implement the following recommendations:

1. Reinforce and expand the participation of the Office of Special Education and Rehabilitative Services in policy decisions regarding the implementation of the Goals 2000: Educate America Act.
2. Allow a limited number of States to experiment with the creative use of Federal funds from several different sources to support the active incorporation of special education into Goals 2000 implementation activities, particularly as they relate to including special education as a resource for all students, families, and school district personnel. The results of these State-level experiments should be studied, promising practices should be identified, and other States should then be given the opportunity to replicate successful practices.

3. Under the implementation of Goals 2000, special education should evolve from its current role as a *place* where a limited number of labeled students are sent to a *support service for all learners* in schools all across America.

SUMMARY AND RECOMMENDATIONS

Over the past twenty years, our nation's special education law, the Individuals with Disabilities Education Act (IDEA), has allowed literally millions of students with disabilities and their families access to a free and appropriate public education. As a result of IDEA, the lives of many students with disabilities and their families have been markedly changed and improved. It is remarkable that this statute, with language crafted more than twenty years ago, has withstood the test of time and societal change in such a powerful fashion. The overall recommendation of the National Council on Disability (NCD) is that no major changes need to be made to the statute itself at this time.

However, it is quite clear that many changes need to take place at the implementation level. NCD recommends that the Federal government develop a much more efficient and effective approach to monitoring the implementation of IDEA, identifying exemplary practices where they exist, citing noncompliance where it exists, delivering technical assistance aimed at improving compliance, and providing effective sanctions for noncompliance. The Federal government can also encourage State and local education agencies to adopt less bureaucratic and mechanistic methods of complying with IDEA's requirements through vehicles such as adopting a noncategorical approach to eligibility; allocating funds based on a weighted presumed incidence model; replacing the requirement that State and local school districts provide a continuum of placements with the requirement that they provide an array of services tailored to the

individual needs of students in the least restrictive environment; removing current fiscal barriers to integrating students with disabilities into typical schools; creating a climate for strengthened partnerships among the Parent Training and Information programs, State education agencies, and local education agencies; urging the adoption of voluntary and impartial mediation processes in areas of conflict between parents and schools; and assuming an overall approach to special education finance that rewards compliance and the achievement of positive incremental change. These are but a few examples of the many recommendations to improve the implementation of IDEA NCD records in this report.

The following is a summary of all of the recommendations NCD has made in this report. These recommendations were developed after consideration of the testimony of nearly 400 witnesses, a review of the results of commissioned reports from 27 nationally preeminent special education researchers and teacher trainers, and examining the results of several studies conducted by the NCD¹⁵ and others¹⁶ regarding the quality of special

¹⁵ See, for example: *Serving the Nation's Students with Disabilities: Progress and Prospects. A Report to the President and Congress* (1993); *The Education of Students with Disabilities: Where Do We Stand? A Report to the President and the Congress of the United States* (1989); *Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities* (1986).

¹⁶ See, for example: SRI International (1993). *The transition experiences of young people with disabilities: Implications for policy and programs*. (Contract No. 300-87-0054). Washington, DC: Office of Special Education Programs, U.S. Department of Education.

education on a national basis. They are categorized by major themes contained in IDEA and Goals 2000.

Zero Reject

The provision of IDEA commonly known as "zero reject" requires that all students, regardless of the nature or severity of their disabilities, receive a free and appropriate public education. Recommendations directed to the Federal government regarding this provision are as follows:

1. Require State and local government entities such as public schools to be accessible to people with disabilities.
2. Improve and expand the process of providing information to *all* parents regarding their rights to access needed special education and related services regardless of the nature or severity of their children's special needs.
3. Clarify and strengthen the requirement that, except in rare instances of imminent danger to self or others, students with disabilities cannot be excluded or removed from school unless an individualized determination is made that their behavior is *not* related to their disability.

Assessment for Eligibility and Nondiscriminatory Evaluation

IDEA requires that State and local education agencies fairly assess students for strengths and needs in a nondiscriminatory fashion, consistent with their native language and mode of communication, and then determine whether a student has a disability, the nature and extent of the disability, and the student's need for special education. Recommendations to the Federal government designed to improve performance and results in this area are as follows:

1. Change the orientation of special education assessment in general from its current quasi-medical model built upon categorical labeling to more individually responsive and relevant assessment measures. Special education can prevent the overidentification of

students by discontinuing the use of evaluation practices that rely upon time-limited data gathered in unnatural settings, which often do not take into account a student's cultural or linguistic background. The identification of students for special education should at least be expanded to utilize functional assessments, diagnostic teaching strategies, evaluations which take place over time in natural environments, and observational and clinical impressions of students' strengths and needs.

2. Encourage State and local education agencies the flexibility to adopt a noncategorical approach to serving students with special needs. This would change the focus of evaluation and assessment efforts from discovering and fitting a student's learning needs into a predetermined list of categories to a focus on determining what types of assistance the student needs and how this assistance might best be delivered.

3. If a noncategorical approach to eligibility is not adopted, students with neurobiological disorders should be eligible to receive special education and related services under the "other health impaired" category, if the assessment team determines that the student has special learning needs.

4. Enforce the requirements that evaluations be done in a student's primary language and be consistent with the student's primary mode of communication (e.g., sign language), that testing take into account the nature of the student's disability (e.g., blindness), that interpreters and translation services are available, and that the student's cultural background is taken into account.

5. IDEA should require coordination between bilingual general education programs and special education programs so that students may avail themselves of the full array of services offered under both of these programs.

6. IDEA should strengthen its parental notification requirements to ensure that parents are given advance notice of their right to participate in their child's education process. This should be accompanied by establishing or strengthening outreach programs directed at minority communities.

7. IDEA should require nondiscrimination training for school assessment personnel to ensure that children from varying cultural and linguistic backgrounds are not subject to discrimination.

8. Fairness in evaluation and placement will be improved by continued support of diversity among special education professionals made possible through funding targeted at minority institutions for the purpose of recruiting and preparing minority college students to enter the special education field.

9. Parents should be given the authority to extend the current 45-day time limit for the completion of an Individualized Family Service Plan (IFSP) under Part H in order to

accommodate families living in rural areas and to ensure that families from diverse cultures fully understand the process and its intended results.

10. The criteria for allowing students with attention deficit disorders, learning disabilities, and neurobiological disorders to receive special education and related services should be based on the student's overall academic, behavioral, and social profile, rather than solely on documented academic failure.

11. Unless there are specific parental or student waiver statements on a student's IEP, it should be presumed that all students with disabilities should be included in the overall school assessment and testing program.

Appropriate Education

IDEA requires education agencies to follow certain processes in educating students in special education (including the development of an individualized education program) and to ensure that they benefit from their education. Recommendations for the Federal government to improve implementation of the many provisions of IDEA contained in this area are as follows:

1. Require State and local education agencies to offer information and training to parents regarding their participation in the special education process, particularly as this relates to active involvement in decisions regarding their child's education.
2. Over the past 20 years, the Individualized Education Program (IEP) has served many purposes. There is currently great variability in the processes used and results derived from the development of IEPs. The Department of Education should succinctly catalogue the overall purposes of IEPs and reaffirm the most basic purpose of the IEP, which is to ensure that students receiving special education are provided with a carefully tailored package of supports and services designed to maximize their educational achievements within the least restrictive environment.
3. Within the context of renewed emphasis on the basic purposes of IEPs, the Department of Education should monitor progress in improving the quality of IEPs. Such monitoring should go beyond the current infrequent and highly formal monitoring program and include new approaches such as stratified sampling of parent and student satisfaction and the solicitation of input from teachers and other professionals on how IEPs might be improved.

4. With the adoption of the recommendations above, the Department of Education should allow greater flexibility —based on informed decisions made by parents and students— on the degree of specificity required in those parts of the IEP that deal with day-to-day instruction and the delivery of related services. For example, some parents feel that there is no need for short-term objectives in their children's IEPs. Other parents would like to see a "shortened" IEP for students with relatively minor disabilities. Greater flexibility in this area would likely lead to greater levels of customer satisfaction and reduced paperwork.

5. The Department of Education should provide incentives and support for State education agencies to improve their monitoring of the performance of local education agencies, particularly in situations where State education agencies are attempting to provide sanctions for substantive noncompliance with the provisions of IDEA on the part of a local education agency.

6. The Department of Education should require State grantees under the Technology Related Assistance for Individuals with Disabilities Act to engage in more extensive outreach to school districts regarding the availability of assistive technology devices and services.

7. More funding should be available to provide necessary assistive technologies and support services that enable students with disabilities to attend school and to increase their independence.

Least Restrictive Environment

IDEA requires education agencies to educate all students with disabilities to the maximum extent appropriate with students who do not have disabilities. Removal from the regular classroom is only supposed to take place after it has been demonstrated that a student is not benefitting from this placement, even after supplementary aids and services have been provided. In order to improve performance and results in this area—one which has been consistently ignored at all levels of government—the Federal government should implement the following recommendations:

1. The goals, purposes, rights, and protections afforded under the Americans with Disabilities Act should be incorporated throughout IDEA through preambular language stating this fact.
2. The requirement that State and local education agencies must provide a continuum of services should be replaced a requirement that State and local education agencies must provide an "array of support services designed to maximize the student's participation in regular education environments and activities." While it may be necessary to maintain many of the current features of the "continuum" as a transition to a "supports and services" orientation takes place, and it may be the case that a relatively small number of students might continue in substantially separate placements (e.g., deaf students), the requirement that a wide array of supports and services be available in regular school buildings will better address the intent of IDEA and other legislation in eventually reducing the number of more restrictive placements.
3. State and local education agencies should be required to develop funding policies and procedures that are at least "placement neutral". That is, funds should be allocated to meet the needs of individual students, not the needs of individual programs. At least the same amount of funding should be available to support a student in an integrated regular education environment as in a segregated program.
4. Removal of a student with a disability from the regular education environment should be documented with a written report attached to the student's IEP. The written report should include: a statement of the supplementary aids and services considered, but rejected, by the IEP team; a statement of the reasons why these supplementary aids and services are not capable of assisting the child within the regular education setting; and a statement as to when appropriate supplementary aids and services will be made available to transition the student back to the regular education environment.
5. The IEP for any child with a disability who is to remain in the regular education setting should list necessary aids and services with the same specificity as the listing of necessary related services, including the time and frequency of delivery of such aids and services.
6. The Department of Education should significantly expand its monitoring and enforcement activities related to implementing the least restrictive environment requirements of IDEA. Given the extreme variability of student placement patterns from district to district and State to State, specific plans and goals for reducing the number of students placed outside of regular education settings should be developed, with receipt of future Federal funding contingent upon meeting these goals.

Parent Participation and Shared Decision Making

IDEA contains many provisions that enable education agencies, parents, and students to share decision-making responsibilities and to collaborate in special education.

To improve performance and results in this area, the Federal government should implement the following recommendations:

1. Expand funding for the Parent Training and Information (PTI) program. PTIs can (and often do) serve as the primary information source for parents regarding special education and offer a cost-effective method of providing this information to parents and family members.
2. Require State and local education agencies to provide parents of students receiving (or being considered for) special education with the name, address, and telephone number of the PTI serving their area. This could be far more cost effective for school districts and would result in improved comparability of information across the State.
3. Parent input can greatly improve educational programs for students with disabilities. However, the current system has the potential to allow parents to request and receive program methods that are unproven, experimental in nature, or dangerous or harmful to the physical or psychological health of their child. Accordingly, there should be an additional State Plan requirement which would require States to certify that no Federal funds will be used to support any individual, program, or practice that employs procedures such as systematic hitting or physical punishment, the application of noxious substances, extended restraint or seclusion, humiliation, and other techniques which—by design—result in pain, physical injuries, psychological damage, hunger, social deprivation, or other harm, that would otherwise be considered as constituting child (or dependent) abuse or neglect if the student were not disabled.
4. The Department of Education should review data regarding the use of surrogate parents under IDEA in order to determine the frequency of use, the roles that surrogate parents actually assume in special education, levels of satisfaction of surrogate parents regarding their experiences with the special education system, and ways to support surrogate parents more effectively in their efforts to provide effective representation for students receiving special education.

Procedural Due Process

IDEA requires education agencies to establish procedures to safeguard the rights of parents and students to procedural due process should they disagree with decisions made by professionals and administrators regarding all aspects of special education programs and services. To improve performance and results in this area (and, hopefully, to make the process fairer and less adversarial) the Federal government should implement the following recommendations:

- 1. Improve and strengthen Federal monitoring and enforcement activities. Under plans for the "reinvention" of Federal processes and procedures, the Department of Education should adopt proven methods of field audit for compliance developed under quality control monitoring mechanisms in the private sector. A major measurement variable in these audits should be customer satisfaction with services. Sampling of customer satisfaction should go beyond State capitals and include visits to less populated and rural areas.**
- 2. Encourage all States to adopt similar audit procedures in their monitoring of local education agency compliance with the provisions of IDEA.**
- 3. When State education agencies are found to be in noncompliance with the provisions of IDEA according to these revised audit procedures, plans for achieving compliance should be developed in an expeditious manner. These plans should include specific remedial actions to be taken, timelines for implementation, and a statement of the potential financial impact for continued noncompliance. Audit findings and plans for compliance should be forwarded to the chief State school officer and the Governor.**
- 4. Encourage States to allow parents and students the voluntary opportunity to seek mediation prior to engaging in full-fledged due process procedures. Mediators should be independent, with no real or apparent conflict of interest with either the local school district or the State education agency.**
- 5. Explore the possible use of binding arbitration as another method of nonlitigative dispute resolution.**

6. Prohibit retaliation by State or local education agencies (or their assigns) against parties seeking to exercise their rights under the due process provisions of IDEA¹⁷

7. Establish effective procedures for final appeal to the Secretary of Education in matters which have not otherwise proved resolvable and publicize the results of these appeals.

Transition

IDEA contains provisions that require education agencies to follow certain procedures to ensure that students will have the skills and opportunities to achieve major life goals (e.g., achieving postsecondary education, employment, and independent living) and that they will transition successfully from special education into adult life. In addition, the implementation of successful programming under IDEA is greatly assisted when students transition successfully from one stage of their education to another. In order to improve performance and results in this area, the Federal government should implement the following recommendations:

- 1. Lower the mandatory age for the initiation of transitional planning from 16 years old to 14 years old.**
- 2. Encourage State and local education agencies to strengthen community-based training and work experiences, inclusive social skills experiences, independent living experiences, and self-advocacy training for students with disabilities in secondary school programs.**
- 3. Require that a member of the transition planning team or that a person appointed by the transition planning team serve as a coordinator for services to be provided under the ITP, integrating these services with those in the IEP.**
- 4. Encourage State and local education agencies to be flexible in the design and implementation of services to students with disabilities between the ages of 14 to 21,**

¹⁷ Retaliatory actions are prohibited under the Americans with Disabilities Act, Section 503. Similar provisions could be incorporated into IDEA.

particularly with regard to the provision of IEP-related services and supports outside of the secondary school campus.

5. The Department of Education should explore the feasibility of continuing the family-based focus of services delivered under Part H to students and families receiving services under Part B of IDEA. Service coordination (case management) should be available as a related service to students and families throughout the transition from Part H to Part B services.

Discretionary Programs

IDEA contains provisions for those training, demonstration, research, and technical assistance programs that Congress has authorized to help Federal, State, and local agencies carry out their duties and to help parents and families be effective partners. In order to improve the performance and results of these programs designed to support special education, the Federal government should implement the following recommendations:

1. State clearly that the purpose of teacher training programs funded under personnel preparation grants is to produce teachers who are highly skilled in providing intensive developmental and remedial instruction to students with disabilities in order to support their participation in the least restrictive environment.
2. Allocate resources to continuing education programs for currently employed special education teachers in order to allow them access to new information and instructional strategies that will enhance their ability to provide high-quality services to students with disabilities.
3. Require that all students preparing to be special education teachers have ongoing practicum experiences in typical neighborhood schools that educate children with and without disabilities in the same age range as children they are preparing to teach.
4. Expand diversity among special education professionals through continuing to target funds to minority institutions for the purpose of recruiting and preparing minority college students to enter the special education field. Moreover, institutions of higher learning in which 25% of the student body is a part of a minority population should be considered minority institutions which qualify for these funds.

5. Continue support for the preparation of teachers with the technical skills required to teach children with sensory impairments and low incidence disabilities and for the training of doctoral students with successful experience in teaching who are committed to training special education teachers upon graduation.
6. Create financial incentives to attract teachers of students with sensory disabilities and low incidence disabilities as well as teacher trainers, through student loan cancellation programs tied to actual work in these areas over a number of years.
7. Create preference in the award of personnel preparation grants to colleges and universities that provide students training in the field of special education with experience in typical education courses and environments that integrate students with disabilities and typical students.
8. Increase funding for the Parent Training and Information centers in order to ensure that all parents —particularly those in minority and rural communities— receive information and support as they become active collaborators in the education of their children.
9. Applicants for funds under the personnel preparation program should be required to describe in their grant applications how they will involve local Parent Training and Information programs in their personnel preparation efforts.

Funding

IDEA defines the Federal share of special education costs and how Federal funds will be allocated. The original target for the Federal funding of the excess costs associated with providing special education was 40 percent by 1982. In reality, the Federal government has never provided more than 8 percent of the cost in any given year. While it is obvious that Federal funding has been much lower than anticipated, 20 years of experience have provided insight into how Federal funds might be best invested in special education. Therefore, in addition to providing sufficient resources for special education, the Federal government should implement the following recommendations:

1. Allocate Federal funds that support the education of children with special needs to the States based on a weighted presumed incidence model, with allowance for factors

such as high numbers of families living in poverty, difficulty of personnel recruitment in rural areas, etc.

2. Increase overall Federal funding for IDEA. Base increases in grants to individual States on the weighted presumed incidence model described above *and* on progress in achieving results such as the following:

- a. Higher graduation rates for students receiving special education;
- b. Steady increases in the numbers of students receiving special education in regular classrooms within typical neighborhood school buildings;
- c. Higher rates of inclusion of students receiving special education in typical student assessment protocols designed to measure overall school district or State performance;
- d. Higher rates of employment as adults for former students who received special education.

All States might be granted a proportional share of the increase during the first three years of funding, with a "special education superfund" beginning in the fourth year to reward those States which have invested the initial funding increase in order to produce better results as described above.

3. Unlike the present situation in which many States essentially reward local education agencies for placing students with special needs in more restrictive settings, require States and local education agencies to adopt and implement "placement neutral" funding practices, wherein at least the same amount of funding is available to support a student receiving special education in a typical school environment as has historically been allocated to place that student in a segregated environment.

4. The Department of Education should consider combining many of its discrete funding authorities into a smaller number of functionally-based programs in order to streamline operations and make funding authorities less confusing to consumers.

Special Education and the Goals 2000: Educate America Act

Goals 2000, the nation's education reform law, includes particular attention to how families, students, and professionals in special education are involved in implementing educational reform. To date, there has been a limited degree of attention

focused on how special education fits into the school reform movement. In order to ensure the increased consideration of the strengths and needs of students with disabilities and their families as the process of reforming the nation's schools goes forward, the Federal government should implement the following recommendations:

1. Reinforce and expand the participation of the Office of Special Education and Rehabilitative Services in policy decisions regarding the implementation of the Goals 2000: Educate America Act.
2. Allow a limited number of States to experiment with the creative use of Federal funds from several different sources to support the active incorporation of special education into Goals 2000 implementation activities, particularly as they relate to including special education as a resource for all students, families, and school district personnel. The results of these State-level experiments should be studied, promising practices should be identified, and other States should then be given the opportunity to replicate successful practices.
3. Under the implementation of Goals 2000, special education should evolve from its current role as a *place* where a limited number of labeled students are sent to a *support service for all learners* in schools all across America.

It is our belief that the adoption of these consumer-based recommendations will serve to significantly improve special education programs across the nation. Within the context of an improved special education program, one that operates as a valued and necessary *service* within schools across America (not as a system apart)¹⁸, the nation's students with disabilities will make much more rapid progress toward attaining the goals of our national disability policy: equality of opportunity, full participation in all aspects of society, independent living, and economic self-sufficiency. In addition, we believe

¹⁸ Education Development Center (1994). *A system apart: A study of the implementation of the least restrictive environment provisions of IDEA in Massachusetts and Illinois*. Newton, MA: Author.

that with the adoption of the recommendations contained herein, the resulting model of special education will serve to support *all* students in achieving the ambitious —yet attainable— achievements envisioned in the Goals 2000: Educate America Act. Thus, significant improvements in the implementation of IDEA can lead to better futures for all of America's children.

Appendix A

Hearing Dates and Locations

The National Council on Disability conducted hearings on the following dates in these locations:

- ◆ October 20, 1994, Anchorage, Alaska
- ◆ November 4, 1994, Albuquerque, New Mexico
- ◆ November 5, 1994, Des Moines, Iowa
- ◆ November 5, 1994, New York, New York
- ◆ November 9, 1994, Philadelphia, Pennsylvania
- ◆ November 10, 1994, Charlotte, North Carolina
- ◆ November 14, 1994, Milwaukee, Wisconsin
- ◆ November 15, 1994, Denver, Colorado
- ◆ November 18, 1994, Boston, Massachusetts
- ◆ November 21, 1994, Berkeley, California

Appendix B

List of Participants and Witnesses

ALASKA

Audrey P. Aanes
Anchorage, AK

Cindy Berger
Anchorage, AK

David P. Berube
Eagle River, AK

Pamela Bickford
Anchorage, AK

John Bolt
Anchorage, AK

Larry Bucholz
Wasilla, AK

Rebecca Campbell
Anchorage, AK

P.J. Carpenter
Fairbanks, AK

Alan Cartwright
Anchorage, AK

Daisy Cartwright
Anchorage, AK

Sandy Clem
Hoonah, AK

Christine Culliton
Juneau, AK

Colleen Deal
Eagle River, AK

Helen Eckman
Anchorage, AK

Carl Evertsbusch
Anchorage, AK

Kathleen Fitzgerald
Anchorage, AK

Jim Henkelman
Anchorage, AK

Teresa Holt
Anchorage, AK

Jenny Hicks
Anchorage, AK

Elaine Hurley
Anchorage, AK

Ann Hutchings
Anchorage, AK

Yvonne Jacobson
Anchorage, AK

Susan A. Jones
Anchorage, AK

Lynne Koral
Anchorage, AK

David Levy
Anchorage, AK

Fran Maiuri
Anchorage, AK

David Maltman
Anchorage, AK

Margaret Mochak
Sitka, AK

Patrick Owen
Anchorage, AK

Darryl Nelson
Chugiak, AK

Sam Reder
Wasilla, AK

Robyn Rehmann
Anchorage, AK

Christopher L. Robinson
Anchorage, AK

Allan Scott

Pamela Carter Simpson
Anchorage, AK

Rick Tessandore
Anchorage, AK

Jane Thiboutot
Anchorage, AK

Linda K. Thompson
Palmer, AK

Tim Wallstrom
Anchorage, AK

Jackie Williams
North Pole, AK

Janel Wright
Anchorage, AK

Michael Young
Anchorage, AK

NEW MEXICO

Dorothy (Joy) Angelino
Albuquerque, NM

Linda Askew
Albuquerque, NM

Rafaelita Bachicha
Santa Fe, NM

Grace Benally
Fort Wingate, NM

Casey and Judy Bonnell
High Rolls, NM

Rebecca Burns
Pueblo Laguna, NM

Patrick M. Caballero
Velarde, NM

Bill Cantrell
Yuma, AZ

Agnes Chavez
Raton, NM

Betty Cope
Albuquerque, NM

Diana Daggett
Albuquerque, NM

Kelly Davis
Santa Fe, NM

John Foley
Albuquerque, NM

Larry Fuller
Dorino, NM

Diego Gallegos
Albuquerque, NM

Ginny Gilmer
Albuquerque, NM

Anna Chavez Gonzales
Carlsbad, NM

Sara Gonzalez
Corpus Christi, TX

Claire Grandora

Patty Jennings
Roswell, NM

Martha Johnson
Bernalillo, NM

Edris A. Klucher
Portales, NM

Michael Klucher
Portales, NM

Carolyn Lavadi
Taos, NM

Leslie Martin Lederer
Albuquerque, NM

Jeannie Manuelito
Bernaillo, NM

Nancy C. McMillan
Santa Fe, NM

Gordon Edward Noz
Tohatchi, NM

Diane Taylor Owen
Fort Wingate, NM

Leah A. Phillips
Albuquerque, NM

Lisa Reader
Los Alamos, NM

Julie Redenbaugh
Albuquerque, NM

Cecilia Riley
Old Laguna, NM

Delfy Roach
Albuquerque, NM

Alberto Rodriguez
Las Cruces, NM

Pauline Romero
Santa Fe, NM

Nannie Marie Sanchez
Albuquerque, NM

Rose Marie Sanchez
Albuquerque, NM

Norberta R. Sarracino
Laguna, NM

Congressman Steve Schiff
Albuquerque, NM

Deborah Doherty Smith
Albuquerque, NM

Grace Spinelli
Fort Wingate, NM

Rebecca Viers
Albuquerque, NM

Pat Wilde
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Mary Zeremba
Albuquerque, NM

IOWA

Evelyn Anderson
Des Moines, IA

Shannon Atkinson
Council Bluffs, IA

Nina E. Baker
Council Bluffs, IA

Diane Beecham
Des Moines, IA

Betty Binkard
Des Moines, IA

Marcie Burow
Des Moines, IA

Kris Christensen
Humboldt, IA

J.D. Danielson
Des Moines, IA

Kathy Davis
Des Moines, IA

Sandra L. Gray Dooley
Centerville, IA

Julie Doy
West Des Moines, IA

Peg Eherenman
Waterloo, IA

Marsha Galina
Des Moines, IA

Patty Gilg
Norfolk, NE

Dawn Gloss
Dubuque, IA

Monica Howard
Glenwood, IA

Lynette Jensen
Ames, IA

Cheryl Johnson
Fort Dodge, IA

E.J. and Ian Jorgensen
Des Moines, IA

Theresa Jozwiak
Bellevue, NE

Tom Laurenzo
Des Moines, IA

Mark, Margaret, and Sara March
Colo, IA

Molly Matthies
Iowa City, IA

Gwen McCollum
Norfolk, NE

Cindy Miller
Griswold, IA

Loveda Mitchell
Lincoln, NE

Betty Nuhuz
Lamoni, IA

Cheryl Ogle
Ankeny, IA

La Rue Olsen
Des Moines, IA

Alex and Greg Omori
Dubuque, IA

Jo Osing
Cedar Rapids, IA

Deb Paton
Reinbeck, IA

Kate Payne
Urbandale, IA

Mark Peterson
Prole, IA

Michael Remus
Columbus, NE

Mary McDonald Richard
Iowa City, IA

Virginia Richardson
Minneapolis, MN

Lyle Richmond
Urbandale, IA

Jill Robinson
Des Moines, IA

Mervin Roth
Des Moines, IA

Bill Rush
Lincoln, NE

Deb Samson
Nevada, IA

Rick Samson
Des Moines, IA

Paula Sandlin
Lamoni, IA

Cathy Smelser
Ames, IA

Nancy Sorenson
Ames, IA

Susie Strait
Villisca, IA

Denita Swenson
Des Moines, IA

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Josie Torrez
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Appendix C

Table of Acronyms

<u>Acronym</u>	<u>Meaning</u>
ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
AEA	Area Education Agency
ICC	Interagency Coordinating Council
IDEA	Individuals with Disabilities Education Act
IEA	Intermediate Education Agency
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
ITP	Individualized Transition Plan
LEA	Local Education Agency
LRE	Least Restrictive Environment
NBD	Neurobiological Disorder
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitative Services
OT	Occupational Therapy
PET	Pupil Evaluation Team
PT	Physical Therapy
PTI	Parent Training and Information
RSA	Rehabilitation Services Administration

SEA	State Education Agency
SED	Severely Emotionally Disabled (or Disturbed)
SH	Severely Handicapped
UAP	University Affiliated Program

Appendix D

Synthesis of Reports from Nationally Preeminent Special Education Researchers and Teacher Trainers¹⁹

Celebrating IDEA's 20th Anniversary

In 1995, Congress and the nation celebrate the 20th anniversary of one of the most significant disability rights laws ever enacted: the Individuals with Disabilities Education Act (IDEA). It is in every respect proper for Congress and the entire nation to celebrate that anniversary. Certainly no other disability-rights law has had such a powerful and positive impact on children and youth with disabilities, on their families, on educators, and on the nation itself.

At the same time, it is also entirely proper for Congress and the nation to recognize that the promises that Congress made in IDEA and the potential that IDEA can evoke in our country's students, families, educators, and communities are still not yet fulfilled. IDEA is like any one who comes out of adolescence and enters young adulthood: some promises have been kept and others await fulfillment. The potential

¹⁹ This synthesis is based on 27 scholarly research papers commissioned by the National Council on Disability, in collaboration with the Beach Center on Families and Disability at the University of Kansas, as part of its work to provide state-of-the-art information from national experts in the area of special education research and personnel preparation regarding the reauthorization of IDEA. The report was prepared by H. Rutherford Turnbull, III, and Ann P. Turnbull based on their own work and the work of the 27 scholars. (Please refer to Appendix E for a listing of these individuals.) It is anticipated that the research papers will be published in the near future.

for their fulfillment is visible, but is in some ways still unimaginable. So much is in place, and so much more can be added. So it is with IDEA: The Act has encouraged and helped students, their families, and the nation's schools to make phenomenal gains, but the results are by no means all that could and should have been obtained.

On the occasion of IDEA's 20th anniversary, it is important to build on the framework and the successes that IDEA has engendered, and to do so on the basis of the best available data about IDEA's accomplishments and shortcomings. In building upon this framework, guided by reliable data, IDEA itself will be improved, and State and local educational agencies will be equipped to implement IDEA even more effectively. It is especially appropriate for Congress to build on the framework and successes in light of the strong grassroots efforts to reform the nation's schools — a movement that Congress itself acknowledged and assisted by P.L. 103-227, the Goals 2000: Educate America Act.

Six Basic Principles Supporting the Implementation of IDEA

IDEA is based on six basic principles which provide a framework within which States may develop effective special education programs. The current status of the implementation of these principles is described below.

- ◆ IDEA's zero-reject principle has opened schoolhouse doors to all students with disabilities; yet schools still try to expel or suspend students who present behavioral or other special challenges.

- ◆ IDEA's nondiscriminatory evaluation principle has ensured that in most cases students' disabilities are identified and fairly and accurately assessed; yet schools still too frequently misclassify students, especially minority students.
- ◆ IDEA's appropriate education principle has helped most students benefit from special education; yet it is abundantly clear that the outcomes of special education are less than acceptable for far too many students.
- ◆ IDEA's least restrictive environment principle has allowed some students to be educated with their nondisabled peers. There has been some progress in physical, academic, and social integration; yet far too often the schools still fall far short in providing the supplementary aids and services that would enable many more students to benefit from education with their nondisabled peers.
- ◆ IDEA's due process principle has held schools and families accountable to each other; yet schools and families still find fault with Federal and State monitoring and still face the financially and emotionally draining prospects of administrative and judicial hearings.
- ◆ IDEA's principle of shared decision making by parents, students, and schools has created effective education and a wholesome system of checks and balances for many of these stakeholders; yet professional dominance still is too often the norm.

In short, however effectively this law and its six principles have been implemented in some areas, there still remain far too many instances where schools have failed to implement IDEA properly.

Islands of Effectiveness, But Not a Mainland

The issue in 1995 is not whether to retain IDEA in its present form. IDEA has been effective. An entire national school-system response has been built on its principles, and countless students, families, educators, and other providers have come to

rely on and apply its principles. Instead, as Congress reauthorizes IDEA, it should focus on the last of IDEA's stated purposes: "to assess and assure the effectiveness of efforts to educate children with disabilities" (20 U.S.C. Sec. 1400(c)). The disturbing findings Congress discovered in 1975 are still reality in far too many school districts in 1995. While it is true that the extent and types of education discrimination have been remarkably curtailed, education discrimination still exists and the equal protection guarantee has not been fully realized. The islands of excellence in special education do not yet constitute a mainland, and general compliance is short of the goal of universal compliance. The issue for 1995, then, is the same issue that Congress identified in 1975: to assure the effectiveness of efforts to educate all children with disabilities.

In 1995, on IDEA's 20th anniversary and as school reform efforts gather speed and power, Congress should assure the effectiveness of efforts to educate students with disabilities in two basic and necessary ways:

- ◆ First, Congress should reaffirm IDEA's basic premises and principles, declaring in no uncertain terms that IDEA is a necessary and useful civil rights law that, through the framework of its six basic principles, implements the Federal equal protection guarantee and the States' own constitutional assurances of universal education for all of their children.
- ◆ Second, Congress should fine tune IDEA itself in a limited number of ways and significantly strengthen Federal, State, and local special education capacities, thereby assuring more effective special education.

Assessing the Effectiveness of Special Education

Congress' reaffirmation of IDEA's basic principles and framework and Congress' capacity-building enhancements to IDEA and its administration should build on the most recent and most reliable data. The National Council on Disability (NCD) has reviewed those data in light of seven questions:

- ◆ **What are the goals of special education?**
- ◆ **How well have these goals been achieved?**
- ◆ **What are the most promising practices for achieving these goals?**
- ◆ **What are the most significant barriers to achieving these goals?**
- ◆ **What should Congress do to further ensure the effectiveness of efforts to educate all children with disabilities?**
- ◆ **What should Federal agencies, especially the Office of Special Education and Rehabilitative Services (OSERS), do to ensure that Federal, State, and local education agencies are most effective in educating all children with disabilities?**
- ◆ **What should State governments and State and local education agencies do?**

The National Council on Disability and the Beach Center on Families and Disability posed these questions to 27 nationally preeminent scholars in special education and personnel preparation, advising them to rely on the most recent reliable data in providing responses, to back up their reports with annotated abstracts of key data-based literature, and to profile programs that exemplify IDEA's proper implementation across all areas of disability. The following represents, in general, what we have concluded after reviewing the data:

- ◆ No matter how effective IDEA has been, there are still significant shortcomings in its implementation. Congress, OSERS, and State and local education agencies should do still more to ensure that every student with a disability has an individualized program of free, appropriate education in the least restrictive environment.

As Congress takes up IDEA on the Act's 20th anniversary, it should again rise to the challenge that it met so well in 1975 and many times thereafter:

- ◆ Reaffirm the basic civil rights of all students with disabilities to effective, equal educational opportunities; reauthorize the Federal framework that has benefitted these students so greatly; and encourage further activities to assure their effective education.

Restating the Purposes and Goals of Special Education

Over the course of the last 20 years and as recently as 1990 and 1994, Congress has stated and restated the nation's policies regarding citizens with disabilities.

Restating these policies now, as Congress considers the reauthorization of IDEA, would seem appropriate. The overall purposes of IDEA are:

- ◆ To ensure equal protection under the law, particularly equal educational opportunity. Such protection is afforded not only in IDEA, but in the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act Amendments of 1975;
- ◆ To assist individuals with disabilities to enjoy lives characterized by equal opportunities, full participation and integration into local communities and society as a whole, independence, self-determination, economic self-sufficiency, and contribution to America. These are also the purposes of ADA and the Developmental Disabilities Assistance and Bill of Rights Act.

To these ends, IDEA has helped State and local education agencies to educate all students with disabilities, no matter what the nature or severity of their disabilities. It

has done so by establishing procedural and substantive rights, providing financial assistance, and providing support for research, training, and technical assistance. What more needs to be done? The answer is straightforward and achievable: Congress should not rely solely on process and substance, but should assure quality in special education. To do that, Congress should review special education's particular goals, as they relate to the nation's overarching disability policy. The goals of special education and IDEA are to:

- ◆ Enhance students' overall capacities: By receiving a free appropriate public education in the least restrictive environment, every student should acquire academic, vocational, and social skills so all can learn, work, live, have social networks, and participate in their communities with their peers who do not have disabilities.
- ◆ Secure students' participation in school and community with peers who do not have disabilities: Students should receive the services necessary for them to achieve success within less restrictive placements and to learn in general education programs, work and reside in typical settings, and have social networks with people who do not have disabilities.
- ◆ Augment families' capacities to respond to their children's special needs: By participating in early intervention and later programs for their children, benefiting from related services, sharing decision making with teachers and other professionals, and participating in the activities of such discretionary programs as Parent Training and Information Centers and model demonstration programs, families should acquire the skills necessary to respond to their children's special needs and to be equal decision-making partners with educators and other professionals.
- ◆ Establish collaboration among families, students, and professionals: Family members, students, and professionals should have the skills to collaborate with each other, and the schools should provide a context for this kind of collaboration.
- ◆ Create a seamless network of effective services through collaboration among service providers and the systems and agencies within which they work: Providers, their agencies, and their service delivery systems should create a seamless network of effective services for students and families, and this

network should enable students to learn, work, live, have social networks, and participate in their communities.

- ◆ **Prepare all professionals to deliver free appropriate public education in the least restrictive environment:** All professionals, particularly general and special educators, should have the attitudes and skills that enable them to be as effective as possible in providing a free appropriate public education to all students in the least restrictive environment.
- ◆ **Carry out model demonstration programs and conduct research to implement IDEA:** Special and general educators, researchers, teacher trainers, other professionals, and families —acting together— should carry out model demonstration programs, provide technical assistance, and conduct research to improve the implementation of IDEA's six principles.
- ◆ **Ensure school restructuring and effective governance:** Students, families, educators and other professionals, as well as community members should reform schools and school governance to advance all of special education's goals. School reform should be sensitive to and accommodate cultural and ethnic diversity in students, their families, and communities.
- ◆ **Assure safe schools:** All schools should be safe for all who use them, and to this end educators and administrators should focus on reducing violence in schools and communities.
- ◆ **Increase and target Federal, State, and local resources:** Federal, State, and local governing bodies should increase their appropriations for special education and permit some funding streams to be used more creatively and flexibly while simultaneously targeting other funding streams to solve particular problems.

Progress to Date in Achieving the Purposes and Goals of Special Education

How successful has special education been in achieving these goals? The answer both heartening and challenging. It is heartening that there are many promising approaches to achieving these goals. Indeed, identifying and applying state-of-the-art practices, supported in large part through Federal resources, has almost always resulted in the achievement of these goals. It is challenging that state-of-the-art exist only in

some school districts. There are islands of effectiveness. However, far too many school districts do not or cannot apply state-of-the-art or best practices. These districts constitute the current mainland of special education.

Promising Practices for Effective Special Education

What are the promising practices, the standards by which effective special education should be judged and the means by which all school districts can deliver effective special education? Promising practices can be found systemwide within a State, districtwide within a local education agency, and personally, for an individual student.

Systemwide Promising Practices

At the State agency level it is especially important to have the following:

- ◆ Professional in-service training through a comprehensive system of personnel development;
- ◆ Model demonstration programs and technical assistance;
- ◆ Strong parent participation in designing, planning, implementing, and evaluating State and local agency plans, relying on a strengthened system of Parent Training and Information Centers;
- ◆ The participation of special education in all school restructuring activities; and
- ◆ Effective monitoring of and technical assistance to local educational agencies.

Districtwide Promising Practices

At the local school district level, it is important to have the following:

- ◆ A zero-reject capacity, including —

- ▶ early screening, identification, and intervention at all ages,
 - ▶ locally adapted services and plans, and
 - ▶ interagency collaboration and coordination of services, systems, and procedures;
- ◆ A nondiscriminatory evaluation capacity, including alternative, nonbiased educational evaluations, especially for minority students;
- ◆ An appropriate education capacity, including —
- ▶ student-focused —not system-focused— individualized education and services that lead to students' mastery of learning skills and strategies,
 - ▶ coherent, easy to use, intensive, and comprehensive services based on validated procedures and methodologies,
 - ▶ a system of comprehensive personnel development that assures that all school personnel will develop the skills necessary to deliver a free appropriate public education in the least restrictive environment, and
 - ▶ adoption and implementation of "safe schools" plans; and
- ◆ A least restrictive environment capacity, including
- ▶ adaptations of general and special education curricula, especially to accommodate students in the least restrictive environment and to accept, in that environment and throughout the district, students who have challenging behaviors,
 - ▶ a full array of least restrictive placement options, with continuous dialogue among special and general educators, school administrators, and families and students about how to secure the least restrictive education for all students,
 - ▶ accessibility and other modifications in the schools' physical environments, and
 - ▶ flexibility in programs and staffing arrangements, with planned times and places for collaboration among educators and families.

Promising Practices with Students and Families

In order to serve students and families in an appropriate manner, it is necessary for school districts to provide the following:

- ◆ **A zero-reject capacity, including**
 - ▶ early intervention to address present special education needs and to prevent additional needs from developing, and
 - ▶ adoption and implementation of a "safe schools" plan;
- ◆ **A nondiscriminatory evaluation capacity, including nonbiased evaluations of students' strengths and needs, especially if the students are from minority populations or present challenging behaviors;**
- ◆ **An appropriate education capacity, including**
 - ▶ developmentally appropriate and professionally validated practices,
 - ▶ appropriate, functional curricula, including instruction for all postschool activities described in IDEA's transition provisions,
 - ▶ instruction in self-determination and self advocacy,
 - ▶ culturally responsive instructional methodologies and curricula,
 - ▶ appropriate extra-curricular activities,
 - ▶ community-based work instruction and work opportunities, including supported employment,
 - ▶ education that teaches not only postschool vocational skills but also other independent living skills,
 - ▶ flexibility in students' schedules so they can take advantage of integrated learning and work opportunities,
 - ▶ use of positive and natural consequences as feedback for appropriate behavior;
- ◆ **A least restrictive environment capacity, including**
 - ▶ education of the student in the most typical settings —neighborhood schools— so that all school environments are integrated by the presence of students with and without disabilities,
 - ▶ age-appropriate and culturally appropriate teaching practices, and
- ◆ **A parent-student participation and collaboration capacity, including**
 - ▶ family-centered services and family involvement, and
 - ▶ professional-family collaboration and shared decision making.

The Application of Promising Practices Across the Six Principles of IDEA

However much progress has been made in implementing IDEA and its six principles, it is clear that improved implementation is necessary and possible. Through applying the promising practices listed above, the implementation of the six principles underlying IDEA would improve in the following manner:

- ◆ **Zero Reject:** Instead of excluding students from school, a variety of successful intervention techniques would be available to support the inclusion of all students in schools, the result being a zero tolerance for excluding any students, whatever the reason.
- ◆ **Nondiscriminatory Evaluation:** Instead of classifying students on the basis of their ethnicity, race, color, national origins or the schools' existing administrative structures, students would be classified according to an accurate assessment of their strengths and needs across the curricular and functional requirements involved in their education.
- ◆ **Appropriate Education:** Applying the promising practices listed above would result in a system of comprehensive and effective services and interventions, effective multidisciplinary and interagency collaboration, and a seamless network of beneficial services.
- ◆ **Least Restrictive Environment:** Instead of current practice, which in many places encourages the segregation of students with disabilities, application of already-proven, promising practices would allow each student to receive his/her education in the least restrictive setting, supported by an individualized and appropriate array of supplementary aids and services that ensure that the student is physically, academically, and socially integrated into general education.
- ◆ **Parent and Student Participation and Shared Decision Making:** With the application of current promising practices, parents, students, and educators would be able to engage in effective collaboration in designing and delivering a free appropriate public education in the least restrictive environment.
- ◆ **Procedural Due Process and Federal and State Monitoring:** The application of the promising practices listed above would greatly reduce the number and frequency of due process complaints and shift the emphasis of Federal and State monitoring and enforcement efforts from tracking "paper compliance" to quality enhancement.

Continuing Barriers to the Implementation of Promising Practices

Implementing the promising practices developed over the last 20 years of experience with IDEA would greatly enhance the quality of education for students with and without disabilities. Still, many barriers continue to impede the implementation of these practices in State and local education agencies. These barriers are as follows:

Zero Reject Barriers

- ◆ Schools are reactive instead of proactive in responding to students' special needs. In particular, they too often exclude students instead of working with them overcome their challenging behaviors.
- ◆ Some schools still do not make the environmental modifications that would increase access, reduce the challenging behaviors of some students, and result in more effective special education.
- ◆ Too often the absence of services and support systems for adults with disabilities restricts the development of effective transition programs for secondary-aged students.

Nondiscriminatory Evaluation Barriers

- ◆ All too often schools rely on testing that targets the students' needs instead of their strengths or testing that simply is inadequate to identify strengths and needs in minority students, thereby causing misclassification, erroneous educational placement, and inappropriate interventions.
- ◆ Similarly, schools pay insufficient attention to the cultural dimensions of their students' lives, and teachers are often not prepared to respond to the cultural diversity of their students.
- ◆ For several groups of students, nondiscriminatory evaluation procedures are themselves inadequate.
- ◆ Placement is still based on the categorical label assigned to students, not on their particular strengths or needs.

Appropriate Education Barriers

- ◆ Schools still use inappropriate curricula.
- ◆ The talents of many teachers and related service providers are misused.
- ◆ Service and support systems are unavailable or ineffective.
- ◆ Services, even within schools, are poorly coordinated.
- ◆ Schools are generally not creative in identifying appropriate interventions or supportive services that might be employed when students are having difficulty in less restrictive placements.
- ◆ Professionals do not know enough about other services available in their communities, particularly those services that could make students' education and transition more appropriate and beneficial.
- ◆ Schools turn too often to "educational faddism" and are driven too frequently by political, rather than sound pedagogical, motives.
- ◆ School systems often lack instructional leadership by highly competent, well-trained administrators, master teachers, and support personnel.
- ◆ Students continue to be disempowered by teacher-directed, deficit-based teaching methodologies.
- ◆ Teachers need a great deal more preservice and in-service training.
- ◆ Curricula often rely too much on specific —and outmoded— models for educating certain categories of students.
- ◆ Teachers may not know how to work with parents or with each other in order to combine their strengths and resources.
- ◆ Competent teachers are in short supply, especially for students with specific types of disabilities.
- ◆ General educators often do not feel responsible for educating students with disabilities.

Least Restrictive Environment Barriers

- ◆ Schools still operate improperly segregated programs and inappropriately place too many students in these programs.
- ◆ Schools still isolate special education students from contact with people and events in their communities.
- ◆ State and local funding patterns create disincentives to placing students in less restrictive programs.
- ◆ State and local agencies still have organizational and administrative structures that perpetuate separate systems of special and general education.
- ◆ Schools still use less intensive special education services for students who need more specialized and intensive teaching.
- ◆ Political and attitudinal factors may lead to a lack of community support for schools' efforts to integrate students with disabilities.
- ◆ Schools may place students into less restrictive placements without the physical, academic, or social supports necessary to ensure that they will experience success in these placements.
- ◆ School districts may have limited less restrictive placement options due to their historic use of more restrictive options.

Parent Participation and Procedural Due Process Barriers

- ◆ Schools often lack sufficient accountability to their students and parents.
- ◆ Schools still suffer from limited parental involvement.
- ◆ Parent Training and Information Centers still do not reach as many parents as they might, especially parents of traditionally underserved or minority students.
- ◆ Some parents are highly resistant to adaptive changes in programs such as less restrictive placement, the use of positive behavioral supports as the intervention of choice for challenging behaviors, or transition initiatives.

Funding Barriers

- ◆ Special education is often underfunded at the Federal, State, and local level.

- ◆ Some funding streams are too restrictive because they either prevent students from receiving special education who could benefit from it or they prevent districts from using the funds more effectively.

Administrative Barriers

- ◆ School districts may have a long history of reliance on categorical programs requiring students to fit the service system rather than the service system to fit the student.
- ◆ Placements may be determined on students' categorical labels rather than on their strengths and needs.
- ◆ Separate systems of special and regular education administration often discourage interdisciplinary and interagency collaboration.

Ideological and Attitudinal Barriers

- ◆ Prejudicial attitudes regarding students with disabilities may exist among general and special educators, among parents, and among members of the general community.
- ◆ Ardor for specific programs or teaching methods can vitiate individualized and effective instruction.

Federal, State, and Local Policy Barriers

- ◆ Outmoded policies still inhibit accomplishment of the goals of IDEA and its full implementation. These policies too often restrict implementation of the principles of appropriate education, least restrictive education, and collaborative decision-making.
- ◆ These policies also stand in the way of effective school restructuring, school-linked services, and safe schools.

Personnel Preparation Barriers

- ◆ Special and general education practices reflect teacher preparation, just as teacher preparation drives school practices. This symbiotic relationship between practice and preparation means that the implementation of promising practices is quite uneven on a national basis.

- ◆ While many students preparing to be teachers benefit from experience with state-of-the-art practices in their education, far too many still do not have access to the quality of practices and preparatory experiences that should have been created by now. Therefore, outmoded and ineffective practices are reinforced and perpetuated.

Recommendations Derived from a Review of Scholarly Research on IDEA

While the implementation of IDEA has certainly not been flawless, it has provided educational opportunity to millions of students who were previously excluded from school altogether. Can IDEA be improved? Can its implementation be improved? The unequivocal answer to both these questions is affirmative. The data reviewed during this research process lead to sound recommendations for improving IDEA and its implementation.

All efforts to improve IDEA, its funding levels and funding policies, and its implementation at the Federal, State and local levels must be premised on capacity building and directed toward improving the abilities of those involved:

- ◆ Improve the ability of schools to deliver services as IDEA envisions them being delivered.
- ◆ Improve the ability of families to collaborate with educators and other professionals in sharing decision-making power related to their children and to service systems as a whole.
- ◆ Improve the ability of students with disabilities to benefit from effective special education and to enjoy lives characterized by integration, productivity, and independence.

Every recommendation made by the 27 nationally preeminent scholars in special education and personnel preparation points to the need to build the capacities of schools, parents, and students in order to improve the implementation of IDEA. A summary of their specific recommendations is provided below.

Recommendations for Improving IDEA

One overall recommendation emerged from a study of the scholarly literature regarding the implementation of IDEA to date:

Congress should reaffirm the basic framework and underlying six principles of IDEA, acknowledge that it is essential legislation for assuring the equal protection and basic civil rights of people with disabilities, and focus on improving the quality of special and general education. Accordingly, Congress should fine tune IDEA and give direction to Federal, State, and local agencies so that they can ensure improved quality of special and general education.

Specific recommendations regarding the six basic principles supporting IDEA and related issues are presented below.

Zero Reject

To improve implementation of the zero reject principle:

- ◆ Incorporate the statement of national goals and policies for persons with disabilities as set out in the Rehabilitation Act and the Americans with Disabilities Act.
- ◆ Change the timelines affecting eligibility for early intervention services and provide more funding for early intervention programs.
- ◆ Require States to put into place systems that ensure collaboration and coordination of transition services.

Nondiscriminatory Evaluation

To improve implementation of the nondiscriminatory evaluation principle:

- ◆ Provide financial incentives in model demonstration, systems change, research, and personnel preparation projects, to ensure the use of nondiscriminatory evaluation instruments and processes with students from minority populations.
- ◆ Fine tune the definitions of "traumatic brain injury" and "severely emotionally disabled."

Appropriate Education

To improve implementation of the appropriate education principle:

- ◆ Provide financial incentives in model demonstration, systems change, research, and personnel preparation projects to ensure the use of best practices such as the following:
 - ▶ special education delivered to minority students in culturally competent ways;
 - ▶ collaboration among general and special educators and related service providers;
 - ▶ interagency collaboration, especially between educational, medical, social service, and other human service agencies;
 - ▶ interdisciplinary and interagency service delivery;
 - ▶ improved transition plan processes;
 - ▶ self-determination curricula as well as teaching and student participation in educational planning and decision-making;
 - ▶ education in the least restrictive environment;
 - ▶ community-based work experiences before a student leaves school;
 - ▶ use of Participatory Action Research techniques in all research, training, and model demonstration programs; and
 - ▶ parent and student participation through shared decision making.
- ◆ Improve technical assistance efforts.
- ◆ Lower the age for mandatory transition planning from 16 to 14.
- ◆ Ensure that students have a greater decision making role in designing and carrying out their programs.
- ◆ Allow students to be eligible for school-based transition services after they graduate.
- ◆ Provide special education students with more useful and credible diploma options.
- ◆ Strengthen transition planning so it focuses not only on work, but also on other post-secondary outcomes.

- ◆ Appropriate more funds for post-secondary programs.
- ◆ Exercise greater oversight with respect to IEP development, implementation, and appropriateness.
- ◆ Allow the low incidence population of students with physical disabilities to be included as one of the focus categories under Subchapter III.

Least Restrictive Environment

To improve implementation of the least restrictive environment principle:

- ◆ Support personnel preparation, not only in special education teacher training but also general education teacher training, particularly in implementing the principles of least restrictive education, collaborative education with other professionals (related service providers and administrators), and relating to families in a culturally competent manner.

Parent-Student Participation and Collaboration

To improve implementation of the parent-student participation and collaboration principle:

- ◆ Extend to older students and their families the family service provisions of the Individualized Family Service Plan now available to infants and toddlers under Part H.
- ◆ Preserve and extend the Parent Training and Information Center programs to better serve minority populations.
- ◆ Enact a presumption that research, training, and demonstration programs will utilize techniques of Participatory Action Research, directing OSERS to award extra credit in peer reviews to research, training, and demonstration projects that use this type of process.

Oversight and Monitoring

To improve oversight and monitoring of the implementation of IDEA:

- ◆ Congress should exercise vigorous oversight and OSERS should conduct more stringent monitoring of IDEA's implementation.

Funding

To improve the implementation of IDEA:

- ◆ Congress should work toward full funding to the authorized maximum (40 percent of excess cost) or create or allow new and different funding streams.
- ◆ Eliminate categorical funding provisions that provide disincentives to delivering special education in the least restrictive environment, and create incentives for more education in the least restrictive environment.
- ◆ Allow more flexibility in using funds for direct services, program administration, and eligibility.
- ◆ Increase model demonstration program funding.
- ◆ Increase technical assistance funding, especially for regional service centers that assist students with visual impairments.
- ◆ Increase research funding.
- ◆ Establish a formula grant category for services and supports that result in the successful employment for secondary level students.
- ◆ Expand Medicaid coverage to allow greater coverage of related services.

Recommendations for the Improvement of Personnel Preparation and Comprehensive Systems of Personnel Development

The special education researchers and teacher trainers were overwhelmingly disappointed by the quality of personnel preparation offered by institutions of higher education and in the comprehensive systems of personnel development operated by State and local education agencies. They unequivocally agreed that a great deal of work needs to be accomplished in the areas of teacher preparation and teacher in-service education.

At present, many recent graduates of the nation's special and general education teacher training programs are not well prepared to apply best practices and state-of-the-art methods. Moreover, State and local agencies' comprehensive systems of personnel development do not effectively remediate the problem created by inadequate preservice training. Similarly, state certification and evaluation standards and procedures for new or continuing teachers do not assure that teachers will be as effective as they should be in the classroom, in collaborating with each other and with professionals in other agencies, and in sharing decision-making responsibilities with parents and students.

These conclusions apply to preservice and in-service programs that focus on categories of disabilities such as learning disabilities, severe emotional disturbance, mental retardation, autism, traumatic brain injury, vision or hearing impairments, physical disabilities, and other health impairments. Likewise, they also apply to programs that focus on skills for early intervention, early childhood education, least restrictive environment and integration strategies, transition, supported employment, school-linked service delivery, interagency collaboration, responding to challenging behaviors through positive behavioral support, and violence prevention.

For example, many early interventionists and early childhood educators still are not utilizing proven successful practices. Special and regular educators are often not trained to carry out the principles of appropriate education and least restrictive environment. That is true, too, with respect to the overarching goal of independence

for individuals with disabilities: Professionals are still not properly trained to enhance students' self-determination and choice-making related to transition and employment. Special efforts are needed to recruit minority professionals as researchers, trainers, and district-based educators, especially for low-incidence populations such as students with hearing impairments. Finally, professionals still lack the necessary skills to collaborate with each other and with parents in making decisions about students' education and about research and demonstration programs.

The good news is that there is a set of promising preservice and in-service practices and programs. The not-so-good news is that these practices and programs have not yet spread across the nation. The result is that, although some professionals receive superb preservice and in-service training, too many do not. Accordingly, students—who have a right to an education that benefits them and does so in the least restrictive environment—are being shortchanged. Education is by definition labor-intensive and labor-dependent. When the labor force—the professional cadre—suffers from inadequate preparation and in-service training, students also suffer.

Since the enactment of the Elementary and Secondary Education Act (P.L. 89-750) in 1966, P.L. 91-230 in 1970, and of P.L. 93-380 in 1974 (the predecessors to P.L. 94-142), the Federal and State governments have shared the responsibility for personnel preparation in general and special education. There is a unique role for the Federal government in developing a national leadership cadre of researchers and other leaders

and in augmenting State efforts to train teachers. The leadership cadre, after all, performs nationally significant roles, whereas the teacher corps performs locally significant roles. By the same token, there is a unique role for State governments, acting through their institutions of higher education. This role is to prepare, certify, and evaluate teachers. This Federal-State partnership is responsible for the present state of affairs in preservice and in-service education, and accordingly the Federal government, State education agencies, and institutions of higher education have joint responsibility for improving preservice and in-service education.

Recommendations Regarding Research

Research should focus on interventions related to student needs. For example, research is still needed to achieve the following:

- ◆ Improve student capacities through early intervention and early childhood special education.
- ◆ Increase students' self-determination and reduce their challenging behaviors.
- ◆ Prepare students for transition into and out of special education and into supported employment.
- ◆ Carry out IDEA's principle of education in the least restrictive environment.
- ◆ Enhance students' social relationships and their abilities to participate with nondisabled peers and adults in the lives of their communities.
- ◆ Ensure that students with challenging behaviors receive positive behavioral support from qualified educators.

Similarly, research is still needed to improve teacher-to-teacher collaboration and teacher-and-parent shared decision-making, and to enhance consumer participation in

setting research priorities, conducting research, and disseminating and using research data. On a different level, research is still needed on the incidence and prevalence of some disabilities, especially mild mental retardation and traumatic brain injury.

Indeed, improved data collection and follow-up studies are particularly relevant to some student populations, especially those with mild mental retardation. Finally, research on larger systemic issues such as nationally important initiatives in school reform, comprehensive services through school-linked service provision, and violence prevention has just gotten underway and should be continued.

In many respects, the research community is just on the edge of significant breakthroughs in preventing and ameliorating the effects of disabilities, improving teaching methodologies, ensuring students' participation in general education and in their own communities, and strengthening and even improving the capacities of schools, teachers, and parents to meet the needs of students with disabilities. Just as teacher preparation is a shared Federal-State responsibility, so too is research. Although the greater portion of special education research funds are provided by the Federal government, there are State-funded and State-supported research activities. Some States have their own research funds, but all States support faculty in their institutions of higher education to conduct research. Thus, both the Federal and State governments can and should respond to these recommendations for research.

Recommendations Regarding Demonstration Programs

By the same token, Congress, OSERS, and State agencies should continue, expand, and redirect model demonstration programs. These programs should include rehabilitation research and training centers, systems-change efforts, technical assistance projects, policy analyses, and short-term (three-year) models to develop and disseminate state-of-the-art and promising practices. Just as preservice and in-service training and research funding are shared between the Federal and State governments, so too with demonstration projects: both levels of government are responsible for improving demonstration activities.

The overall effect of model demonstration projects is to develop new and improved techniques for teaching students, advancing IDEA's six principles (especially the least restrictive environment principle), and preparing special and general educators, families, and students themselves for collaborative decision making. Historically, these demonstration programs have been at the forefront of advancing IDEA's purposes and goals. At present, they need to be significantly more targeted on current implementation and improvement issues.

Recommendations for Policy Revision

As noted above, many Federal, State, and local policies are problematic. Too often policies impede schools from implementing the principle of the least restrictive environment, and too rarely do they create incentives for schools to implement that

principle. In some States, teacher union contracts limit regular or special educators in implementing the principle of the least restrictive environment. Moreover, some State laws, such as the Nurse Practice Acts, impede educators and other professionals from delivering school-based services to students with health-related needs.

Better Federal and State-level interagency collaboration is required, especially to improve services to students with severe emotional disabilities and traumatic brain injuries and to help students with visual impairments have easier access to printed materials. In addition, the purposes, goals, and rights guaranteed under the Americans with Disabilities Act need to serve as the basis for future policy discussions and decisions regarding special education and the delivery of services to children and youth with disabilities.

Recommendations for Improvements in Special Education Practice

Congress, OSERS, and State and local agencies must take action to improve special and general education practices. Practices that reflect state-of-the-art service delivery are well known. They are in place and have been in effect for quite some time. The problem is that these practices are the exception, not the rule. Once again, islands of excellence do not constitute the mainland.

State and local education agencies are responsible for delivering special education. They are responsible for assuring that education benefits students and is

delivered in the least restrictive environment. Unfortunately, far too many State and local agencies fall short in using promising practices and state-of-the-art services that would help them effectively discharge their responsibilities in the areas of appropriate education and least restrictive environment for students with disabilities. In particular, appropriate services are still unavailable consistently and uniformly throughout the country to students who have been classified as having, among other disabilities: learning disabilities, severe emotional disturbance, mental retardation, severe and multiple disabilities, other health impairments, autism, traumatic brain injuries, visual impairments, and hearing impairments. For many of these students, curricula are ineffective and dated. Their transitions from school to adulthood are haphazard. It is not the least surprising, then, that the results of their education are so disappointing.

Indeed, there also is evidence of a paucity of services—not merely an absence of best practices—for students with traumatic brain injuries, visual impairments, and hearing impairments. There is also evidence that minority students, as well as children in early intervention and early childhood education programs, are especially shortchanged by the lack of any services or the lack of appropriate services. It is one thing to lack services altogether or to not have appropriate education even if some services are provided. These problems are compounded when services are finally provided that do not reflect state-of-the-art or promising practices for serving students in the least restrictive environment.

In early intervention, early childhood education, and throughout the elementary-to-upper school years, practices in special and general education simply do not sufficiently comply with the principle of least restrictive environment. Much more could be done to decentralize large centers where too many students receive their education and to disperse specialized services throughout their home communities. The restructuring and dispersal of presently centralized services are long overdue. While it is true that some students still need highly specialized services, they need to have access to an array of services which will meet these needs in their home communities. Most students currently placed in these centers can be educated to a much greater degree in general education. Their current levels of physical, academic, and social integration leave a great deal to be desired.

Another problem with current practice is found in the relatively low quantity and quality of parent-student participation and collaboration. While many parents do share decision-making responsibilities with special and regular educators, there is compelling evidence that many do not and that the reasons for this noninvolvement have less to do with their willingness and capabilities to be part of their children's education teams than with educators' attitudes and practices. Time and again, schools and educators are reluctant to share responsibilities and decision-making powers with parents and students, to schedule meetings at times and places convenient to parents and students, and to develop the skills to collaborate with parents and to teach self-determination to

students. In short, there are administrative, attitudinal, and skill barriers to implementing this important principle.

To improve performance in the areas of appropriate education, least restrictive environment, and shared decision making, State education agencies need to put into place more regular and stringent systems for monitoring local agencies. Monitoring involves more than paper-compliance reviews: It has to involve scrutinizing the actual quality of special education services. Moreover, monitoring and quality assurance have to be proactive. That is, they must involve technical assistance and improvements in comprehensive systems of personnel development, targeting resources toward improving the skills of special and regular educators to deliver an appropriate education in the least restrictive environment to students with disabilities in collaboration with one another and with parents and students.

The need for interprofessional and interagency collaboration and coordination is one that State and local education agencies must address during the next five years. To deliver services in the least restrictive environment, to assure transition from school to postschool opportunities that IDEA and ADA envision, and to make certain that school restructuring benefits students in special education, State and local education agencies — and especially State agencies as they monitor local agencies— have to reconceptualize themselves. They have to be willing and able to move from separate systems of special and regular education to a unified system where all schools "own" all students, where all

indeed means *all*, and where, if necessary or desirable, school-linked services emanate from comprehensive schools.

This shift will require State legislatures to design funding streams that unify school district administrative structures and services. It also will require State legislatures to ensure that State funding is based on the number of students needing special education (not just the number receiving IEPs), and on the needs of the students themselves (not on the categories into which they have been classified). State and Federal funding has been too closely tied to the number of students having IEPs, thus penalizing States that provide special education to those who need it but who may not have an IEP. Furthermore, State and Federal funding has been tied too much to categories of disability, so that students with a certain classification receive certain types and levels of service, rather than receiving what they actually need, without regard to their classifications.

In summary, State and local education agencies and even State legislatures themselves should move aggressively to adopt the promising practices that research, demonstration, and personnel preparation programs have developed and validated over the past 20 years of experience in special education, including reconfiguring service delivery, monitoring methods, and funding policies. It is clear that the knowledge base exists to improve special and general education practice. It is also clear that State and

local education agencies and State legislatures have not, to date, put that knowledge to best use.

Recommendations for School Restructuring

The opportunities —and the risks— are high as State and local agencies begin to restructure themselves pursuant to the Goals 2000: Educate America Act.

Opportunities exist to create new norms and forms for all students, to reshape schools so that excellence and equity coexist, especially for students with disabilities. Indeed, to the extent that comprehensive schools, serving as the hub of school-linked human services, can be created as restructuring moves forward, the chances increase for wider implementation of the principle of least restrictive environment. However, intensive oversight by Congress, OSERS, and State agencies is especially warranted due to the risk that school restructuring will proceed without special education constituents being substantially involved and will result in school norms and forms that reduce opportunities for students with disabilities to receive education in the least restrictive environment in neighborhood schools.

Summary

As Congress considers the reauthorization of the Individuals with Disabilities Act on the 20th anniversary of P.L. 94-142, the indisputable conclusions to be drawn from a review of scholarly literature and the work of nationally preeminent scholars in the fields of special education research and teacher training are as follows:

- ◆ **IDEA advances the equal protection doctrine of the Constitution. It is not one of the so-called "unfunded mandates." It is, instead, Federal assistance to the States so that the States and their local education agencies can carry out their own Federal and State constitutional duties to educate all children with disabilities.**
- ◆ **IDEA has been the single most significant vehicle for creating and implementing effective special education. Its 20-year history of positive impact on students, their families, educators, other professionals, and communities is both obvious and impressive.**
- ◆ **Congress, OSERS, and State and local educational agencies must, however, improve IDEA and its implementation. The improvements will link the current islands of excellence in special education to the educational mainland. In time, they will create the mainland itself. When that happens, all students—those with and without disabilities— will benefit, all families and educators will benefit, and indeed the whole nation will benefit from the investment we have made through IDEA in advancing equality of opportunity, full participation, independent living, and economic self-sufficiency for students with disabilities.**

Appendix E

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3. Serious Emotional Disabilities, by Lucille Eber and C. Michael Nelson.
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2. **Early Childhood**, by Michael J. Guralnick.
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4. **LRE/Early Childhood**, by Samuel L. Odom.
5. **LRE/Elementary and Middle School**, by Kathleen Gee.
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7. **Self-Determination**, by Michael Wehmeyer.
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17. **Violence Prevention**, by Hill W. Walker.

Appendix F

A Brief Description of the National Council on Disability

Overview and Purpose

The National Council on Disability is an independent Federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The National Council was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed the National Council into an independent agency. The overall purpose of the National Council is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of the National Council includes the following:

- * Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; and all statutes and regulations pertaining to Federal programs which assist such individuals with disabilities in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities;
- * Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the Federal, State, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access for health care, and policies that operate as disincentives for the individuals to seek and retain employment.
- * Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of Federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and

inclusion and integration into all aspects of society for Americans with disabilities.

- * Providing the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information which the Council or the Congress deems appropriate;
- * Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.);
- * Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended;
- * Providing advice to the Commissioner with respect to the policies of and conduct of the Rehabilitation Services Administration;
- * Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities;
- * Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of such Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities;
- * Preparing and submitting to the President and the Congress a report entitled *National Disability Policy: A Progress Report* on an annual basis; and
- * Preparing and submitting to the Congress and the President a report containing a summary of the activities and accomplishments of the Council on an annual basis.

Population Served and Current Activities

While many government agencies deal with issues and programs affecting people with disabilities, the National Council is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy which affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual

circumstance. The National Council recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by assuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

The National Council plays a major role in developing disability policy in America. In fact, it was the Council that originally proposed what eventually became the Americans with Disabilities Act of 1990. Our present list of key issues includes monitoring the implementation of Federal civil rights laws affecting people with disabilities, analyzing the performance and results of special education programs, development of a national approach to personal assistance services, health care reform, the inclusion of students with disabilities in high quality programs in typical neighborhood schools, equal employment opportunity, community housing, improving assistive technology and access to the information superhighway, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

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